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# Poetizing disability : arts-informed reflections

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Poetizing Disability: Arts-Informed Reflections

by

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## ABSTRACT

Through arts-informed educational research, I engaged in poetic exploration of the lived experience of disability. Theorizing and creating through poetry helped me to reflect and deepen my understanding of my own disability, cerebral palsy, as well as my adolescent participant's struggles and joys with dyslexia. I discovered that a person with dyslexia, an invisible disability, can have similar emotional experiences to those I had as an adolescent female with cerebral palsy, including some difficulty relating to peers. My participant revealed that while she accepts the diagnosis of dyslexia, she does not consider dyslexia a disability. Thus far, both my own and my participant's diverse schooling experiences have helped us to do well. Our success is due largely to the emotional and academic supports we enjoy at home and at school.

## CHAPTER 1: INTRODUCTION TO THE STUDY

Parents  
teach us  
never say can't  
Dyslexia a different brain  
Dyslexia different way of seeing  
messages stay with us  
like a prophecy  
self fulfilling  
life

I have had cerebral palsy (CP) since birth. Individuals with CP have difficulty controlling or moving muscles. CP is an injury to the brain which occurs before or during birth. Persons with CP experience different levels of difficulty depending upon the severity of the disability. Some people, including myself, are able to walk while others use wheelchairs. A person's ability to speak may also be affected. My lived experience with this physical disability has inspired me to understand others with disabilities. As an adolescent female, I struggled with the reality of my disability. At that time, I did not think of myself as disabled because I could do most things for myself. Others had difficulty understanding that I did not see myself as disabled because to them, I obviously was disabled. Relating to my peers was difficult. Through the process of emotional maturation, I have come to accept that I have a disability and that I need assistance with certain things. I have found that some people will accept me, but others will not. As I mature, I am more accepting of my reality. While learning to accept myself, I have become interested in and accepting of others with disabilities. This has given me the desire to study disabilities.

I was hoping to find common threads in our experiences so that I would perhaps have greater understanding and empathy for students that have this disability in the future

### Purpose of the Study

This arts-informed study was framed within phenomenology (Cole and Knowles, 2008; van Manen, 2006). A phenomenological study is concerned with understanding the lived experience from the point of view of subjects. (Bogdan and Biklen, 2007). The study focuses on the lived experience of an adolescent female from Northern Ontario who is living with dyslexia. Dyslexia is classed as a learning disability in which a person typically experiences difficulties with fluent reading and/or reading comprehension for reasons that cannot be explained in terms of sensory, cultural, intellectual difficulties socio-economic or schooling disadvantages. There may also be spelling problems and difficulties decoding words to sound. Childhood symptoms of dyslexia may also be accompanied by problems learning the alphabet, letter names and math facts. In adolescence, dyslexics may experience slow reading speed, poor performance on timed tests involving language skills, difficulty completing homework and problems with reading comprehension.. My participant experienced all of these symptoms except that she had no difficulty learning the alphabet. Similar to persons with CP, individuals with dyslexia experience varying degrees of this disability.

The participants, as well as the schools that my participant attended, are given pseudonyms. The primary participant is Mallory. The main research question during our conversation asked, "What is your lived experience as an adolescent female with dyslexia?" I also conversed with Mallory's parents, Leigh and Scott, asking them, "What is your lived experience as the parent of an adolescent female with dyslexia?"

Throughout this investigation, I asked myself, “What is my lived experience as a woman with a disability?” and “How is my experience similar to or dissimilar from my participant’s lived experience?” For this study, I utilized multiple data sources, including the following:

1. Tape-recorded conversations with Mallory (one lasting 1 hour) and one with each of her parents (two conversations lasting 1 hour each).
2. My journaling and Mallory’s journaling (15 minutes per day for 2 weeks).
3. Mallory’s creative writing.
4. Mallory’s assessment for dyslexia from the Lakehead Regional Family Centre.
5. Mallory also sent me an e-mail in response to a question that I posed.
6. Field notes which I compiled after each conversation

It was interesting to explore ways in which our experiences have been similar yet different. The poem at the beginning of this chapter expresses how Mallory’s and my parents influenced our thoughts and attitudes towards our disabilities. When my parents told me not to say the word “can’t”, it gave me strength not to give up. For Mallory, accepting dyslexia was a process. When she was a small child and Leigh, her mother, was trying to home school her, it was difficult to discover what would work. Both of them were frustrated. As she grew, she gained and is still gaining self acceptance and confidence. When Mallory’s parents told her that her brain works differently, this greater understanding of her condition also gave her strength. Because of what our parents have taught us, we each have a fulfilling life. In addition to having greater understanding of



myself and Mallory, I feel that this experience has made me a more empathetic and compassionate teacher. I hope to have an impact on others' understanding of disabilities.

I approached this study on disabilities through arts-informed educational research. In arts-informed research, the researcher collects and expresses the data via many artforms from visual art to dance. I have created poetry and other creative writing which I composed after each conversation. This allowed me to more fully appreciate, understand, and express each participant. Cole and Knowles (2008) assert:

Arts-informed research is a mode and form of qualitative research in the social sciences that is influenced by but not based in the arts broadly conceived. The central purposes of arts informed research are to enhance understanding of the human condition through alternative (to conventional) processes representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible. The methodology infuses the languages, processes and forms of literary, visual and performing arts with the expansive possibilities of scholarly inquiry for the purposes of advancing knowledge. (p. 59)

Many aspects of art- informed research are similar to arts-based educational research. For example, the experience that the poetry speaks to the reader independently of the poet (Blaikie, 2007), hence, I include information about arts-based educational research in this thesis.

### Rationale for the Study

I have spent considerable time studying special education. Having conducted an arts-informed educational research study, I have a better understanding of dyslexia. Perhaps I will now be more able to help students with this disability to experience the joy of literacy. Children often find it difficult to cope with dyslexia. Singer (2005) writes about the bullying of dyslexic children by their peers:

A growing body of research shows that their academic problems are related to a wide range of psychosocial problems, such as inattentiveness low motivation for school work, dropping out of school, fear of failure, depression, anxiety, loneliness, low self esteem and poor peer relations. Children with dyslexia, like all children with learning disabilities (LD), are also at greater risk of being bullied by their peers. (p. 411)

This assertion could very well be true because anyone who is perceived to be different may be considered a target for individuals who are likely to bully. Dyslexia is viewed as a weakness, and bullies feel more powerful and are able to hide their own weaknesses by bullying others. Having read studies published by Singer (2005) and others, I chose to have a more intimate look at the situation of one participant and her family; This study is unique in that each participant's lived experience brings with it his/her own perspective. There has been much research focusing on males with dyslexia. This case study investigates a female experience of dyslexia to yield a fresh perspective. The following excerpt from Singer's (2005) research expresses clearly how a dyslexic child feels when being victimized:

In kindergarten, I was a bit bossy to the other children. I thought I was the best and the smartest. Then I found out I was not the best--and I was even bad at learning. I was shocked! Being teased is the most terrible thing that can happen to you. (Jona, 11) (p. 411)

In this study, I wanted to explore whether adolescent females experience similar teasing among other things. Mallory did not express that she had been openly bullied. In her case, the action is more covert and subtle, but she is aware of it, saying that she cannot be herself with some people. Hence, it is essential to enable students with dyslexia to advocate for themselves when they are among those who do not have their disability .Kathy Buckley, a comedienne who has a hearing impairment, has used her prominent place in the entertainment world to help others understand her disability. She asserts:

My comedy disarms people. I truly believe that the only disability out there today is attitude....I love to make people laugh, but I love even more if I can teach them something at the same time....Every child has something to contribute....There are no broken children, none need fixing. Don't judge a book by its cover. Open the book and get past that cover (as cited in D'Agostino, 1997, p. 45)

Mallory has a strong desire to help others understand dyslexia, which she demonstrated by doing her Science Fair project on the topic. Participating in the research for this thesis gave her further opportunity to let her voice be heard. Also, during the conversations, her parents spoke openly about Mallory, their relationship with her, and their views about dyslexia and disability in general.

This paradigm and our contributions of creative writing are unique because of the nature of arts-informed educational research and phenomenology. Existential phenomenology examines the experiences of the participants as they are situated in particular circumstances (van Manen, 2006). This is valuable to research because each of us has different lived experiences, yet the experiences are able to strike chords of similitude. This was evident to me while I was conducting this case study. Mallory and I are both Christians, which profoundly influences the way we see the world. It definitely influenced me when I was writing the poetry. We have both experienced difficulties regarding friends' reactions to our disabilities. In arts-informed educational research, the poetry communicates directly to the reader, and each reader brings something new to the experience that is independent of the researcher's experience (Blaikie, 2007). Arts-informed educational research reaches a broader audience through art forms. This study may cause scholars, teachers, parents and other interested parties to pause and ponder the questions of dyslexia anew and relate them to other disabilities.

## CHAPTER 2: LITERATURE REVIEW

### Review of the Literature (1987-2008)

A scholar's service  
Bridges gaps in tolerance  
Informs humankind

The following literature review includes studies about adolescence and dyslexia between the years 1987 and 2008. The findings regarding the physical changes in a dyslexic brain are explored as well as the social impact dyslexia has on individuals' lives. I felt it was important to understand adolescence in general because my participant is an adolescent. I then sought to understand dyslexia.

#### Adolescence

Regarding the issue of the emotional growth experience of adolescents, Ybrandt (2008) declares, "This is a developmental period characterized by at least some 'storm and stress' in which young people try to find answers to questions of identity and of what social behaviours are appropriate in different social contexts" (p. 2). She asserts that although most adolescents weather these years well and emerge with a positive self-concept, some internalize their problems, which may be exhibited by depression, anxiety, somatic complaints, and withdrawn behaviour, and some externalize their problems, which may be characterized by acting-out behaviours that may include delinquency and aggression.

Ybrandt (2008) posits that self-love is "a strong determinant of all other aspects of the self concept" (p. 4). A healthy self-concept influenced by self-love exhibits some issues of adjustment as well as goal orientation, self-discipline, and the freedom to develop according to one's own nature. Positive self-concept relates to fewer problems

with internalization and externalization in adolescence. Boys tend to externalize, whereas girls are more likely to internalize. Adolescents who are 15 and 16 are found to have more problems than older and younger adolescents. “Similarly, the prevalence and nature of stressful life events and the greater psychosocial pressure on girls than on boys are found to contribute to fluctuations in self image” (Ybrandt, p. 11).

Because of the malleability of adolescents’ self-concept, parents have a pivotal role in shaping adolescents’ personality; they must not shirk this responsibility in the name of letting young people “find themselves.” Sometimes parents allow their adolescent children a lot of freedom thinking that if they do this the child will naturally find their best path in life. According to Hair, Moore, Garrett, Ling and Cleveland, (2008) adolescents need guidance. “High quality parent-adolescent relationships predict lower levels of adolescent depression and delinquent behaviours” (Hair, Moore, Garrett, Ling, & Cleveland, 2008, p. 187). Practices such as awareness or monitoring, supportiveness, strictness, and family routines characterize quality parent-youth relationships. From these relationships, positive youth and adolescent outcomes are predictable; parental awareness predicts healthy preadolescent psychological adjustment. With parental support, there are reduced levels of depression, and moderate levels of strictness foster a sense of protection. Family rituals encourage adolescents’ sense of identity and self-esteem, and discourage conduct disorder and disruption.

One of the responsibilities of parents is to guide adolescents gradually into making their own decisions. Adolescents certainly have opinions about whether their parents should influence certain decisions. Daddis (2008) conducted a study on how adolescents decide which issues should be at their own rather than their parents’

discretion. As children grow older, peers play an increasingly greater role in their lives. This would suggest that during adolescence, a particularly vulnerable time, peers influence each other even more than they had previously. According to Daddis (2008), “It is not surprising, therefore, that friends have been recognized as an increasingly important influence on a range of issues such as social problem solving skills, interpretations of social cues, school adjustment and engagement in risk behaviours” (p. 77).

The adolescents in Daddis’s (2008) study express that once they leave home, their friends should influence them more than family should. In contrast, during middle and high school, they continue to seek parental approval in forming their standards and long-term goals. With friends, they develop personal taste, identity, and orientation toward adolescent culture. Adolescents also rely on their own judgment. Daddis reports:

Indeed, a subjective sense of self reliance, marked by independence of thought, internal locus of control and assertiveness increases during the transition to early and middle adolescence. With age, adolescents may become more likely to reference their own judgment and experience in deciding when and if they are ready to exert decision making control over a specific issue. (p. 78)

They also agree with their parents that parents should have authority regarding moral and conventional issues; however, they expressed the desire for more authority over their social world than their parents deemed wise. The adolescents comment on being influenced by what goes on in their friends’ homes. They may or may not want similar rules and boundaries. As adolescents grow, they push the boundaries between personal and parental jurisdiction. This is a reality in the average adolescent’s life.

## Disability and Adolescence

Disabilities influence an adolescent's experience. A number of potentially interacting variables contribute to the complex phenomenon of dyslexia. Lyon, Shaywitz, and Shaywitz (2003) define dyslexia as follows:

Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge. (p. 1)

This is a widely accepted definition that can be applied to children who speak English and experience dyslexia. Phonological problems are more common for the beginning reader in English. It is often impossible to identify any neurobiological cause; hence this definition as to cause is not without controversy. In addition, concerning the presence of dyslexia in children whose first language is not English, Chan, Ho, Tsang, Lee, and Chung (2006) declare:

Despite the accumulating body of supporting evidence, the centrality of the phonological deficit hypothesis as the root deficit in developmental dyslexia has not gone unchallenged. Essentially researchers in their studies with languages other than English have independently arrived at the conclusion that cognitive deficits other than phonological processing might assume greater importance in some languages....Specifically slow naming speed which might indicate the disruption of the automatic processes involved in extracting orthographic patterns, could represent a second core deficit in dyslexia. (p. 544)

These researchers adopt the view that there could be multiple deficits and that in some languages, the phonological deficit may not be the primary one; hence, in theory, the relationship between listening and reading that exists in English may not be present in

other languages. Note that phonological problems most often are not the main feature of older English speaking children with reading problems.. Dyslexia is a complex disability that warrants further study.

Tsesmeli and Semour (2006) conducted a study to determine whether dyslexia is associated with difficulty in spelling morphologically complex words. They also wanted to ascertain whether the special difficulties could be explained in terms of underlying linguistic difficulties. The study reveals that “dyslexia was not characterized by an exaggerated difficulty in spelling morphologically complex forms, but rather by a fundamental (phonographic, lexigraphic) deficiency which combined additively with the effects of the greater complexity of derived forms” (p. 613). These researchers found that “dyslexic difficulty in spelling cannot be attributed to poor vocabulary knowledge” (p. 599). They also assert that “metamorphology was deficient relative to age but only to a degree consistent with the reading level which had been achieved, suggesting that morphological awareness may be a product of literacy rather than vice versa” (p. 616).

Individuals with dyslexia often have difficulty not only reading and spelling but also writing. Berninger, Nielsen, Abbott, Wijsman, Raskind (2008) investigated the relationships between handwriting and spelling and whether these relationships are different for people with dyslexia. One of their goals was to make people aware that the problems the people with dyslexia may have with writing are more than a lack of motor skills. Writing is more than a motor skill, it is an orthographic skill. Consider the following:

Children with dyslexia were impaired in handwriting,....spelling.... and written composition. The children did not have, on average, related oral language problems as assessed with behavioral tests (e.g., in morphological and/or syntactic awareness) or histories of significant language delay or oral language problems



during the pre-school years.... Grapho-motor planning did not contribute uniquely to written expression in either the children or adults with dyslexia. For children with dyslexia, grapho-motor planning was significantly correlated only with word form and not with phonological loop, executive support or written expression...grapho-motor planning may contribute indirectly to composition through the orthographic word form in children and adults with dyslexia. (Berninger et al., pp. 11-12)

Further, the word form factor influenced their oral reading accuracy. Berninger et al.'s findings suggest that "the contribution of oral motor planning is only evident in children with dyslexia when it has to be orchestrated with other working memory components for the purposes of fluent reading" (p. 13). The researchers hypothesized that grapho-motor planning would significantly influence the outcome of their research in terms of correlation with the phonological loop, executive support or written expression.

Altmann, Lombardino, and Puranik (2008) write, "Children with dyslexia are reported to have difficulties with verbal fluency as well as syntactic deficits or delays although the latter findings are controversial" (p. 56). These researchers affirm that there is a slower rate of phonological and orthographic processing and deficits in working memory, word retrieval, naming speed and cross modal integration in at least some dyslexic individuals. They use a broad definition of dyslexia, which includes pure phonological dyslexics, language-impaired participants, and an overall delayed group. The pure phonological dyslexics did poorly on the morphological test. Altmann et al anticipated that sentence generation, the primary task in this study, would be difficult for dyslexics because it is a complex process that "involves the generation and integration of many levels of linguistic material" (p. 57). They also comment that "a literate person's lexicon comprise semantic, phonological and orthographic representations that are interdependent" (p. 57). Because the quality of phonological representations of a person

with dyslexia would be compromised, the development of semantic and orthographic representations is also often affected.

Altmann et al.(2008) found significant differences in the sentence generation of participants with developmental dyslexia when the results were compared to what is termed a normal reader. In particular, fluency, completeness, and grammaticality were observed. The participants with dyslexia had fewer complete responses than normal readers, as well as fewer grammatical responses. In addition, the dyslexics tended not to resolve fluency issues as they got older.

Although every study that I read concurred that there are phonological deficits, the fact that there were disagreements is significant because the ratio of males to females who have dyslexia changes depending upon the criteria applied to diagnose the disability. When Miles, Haslum, and Wheeler (1998) tested patients, phonological difficulties were observed as well as difficulties in spelling and reading despite average or better intelligence. There was also confusion over left and right. When Miles et al. tested patients who exhibited phonological difficulties, difficulties reading and spelling in relation to general intelligence, confusion over left and right, and difficulty recalling orally presented numerals, the ratio of males to females having dyslexia was 4.51:1. Further, if the diagnosis of dyslexia was based upon reading and spelling difficulties only, the ratio was closer to 1:1 (Miles et al., 1998).

Even if traditional criteria are used, females are affected by this disability, and they must not be ignored. There are often fewer females in special education classes (Coutinho and Oswald, 2005). Kratovil and Bailey note:

Males with disabilities are identified for special education services 1) more frequently, 2) at a younger age, 3) with a higher level of intelligence, and that

4) males with disabilities more easily and more frequently received related and support services once in special education. (as cited in Wehmeyer and Schwartz, 2001, p. 273)

Coutinho and Oswald explain that particular factors, such as slower maturation, complications during gestation and childbirth, and genetic predispositions, may make males more susceptible to certain disabilities than females.

Even though studies have supported the claim that more males than females struggle with dyslexia, I explored the female experience with dyslexia because females, who often have been excluded from past research, need to be understood, especially by educators and parents. With such information, educators will be better equipped to meet the needs of adolescent females with dyslexia (Rousso and Wehmeyer, as cited in Wehmeyer and Schwartz, 2001; Traustadottir, 1990). It is helpful to understand the physical reality of students' brains affected by dyslexia. Mallory finds that the more she understands dyslexia, including how the brain works, the better she is able to accept herself as an adolescent female with dyslexia. In addition, the more researchers understand this disability, the more prepared they will be to make suggestions regarding the successful teaching of persons with dyslexia.. Some researchers speculate that neurons in the brain of a dyslexic individual fire differently than in a non-dyslexic brain. Katzir and Pare-Blagoev hypothesize that technology (e.g., and electroencephalogram) can help to screen for babies who are at risk for dyslexia (Katzir & Pare-Blagoev, 2006).

Boets, Wouters, van Wieringen, and Ghesquiere (2005) propose a hypothesis regarding the phonological deficit. They suggest, "One hypothesis maintains that this phonological deficit results from a more fundamental deficit in the basic perceptual mechanisms that are responsible for auditory temporal information processing" (p. 64).

The findings did not support the aforementioned hypothesis. However, the administration of a battery of tests for this research, including phonological tests, sound identity tasks, a nonword repetition test, a digit span forward test, a rapid automatic naming test, a letter knowledge test, a productive letter knowledge test, auditory tests, a GAP detection test, a frequency modulation test (FM), a tone in noise detection task and a psycho-physical procedure confirm findings of previous research (Boets et al.). Because dyslexia seems to have a genetic link for some, the participants included a high-risk group who have family members with dyslexia and a low-risk group with no family members having dyslexia. The findings revealed no significant differences in verbal short term memory or rapid automatic naming, but significant differences in phonological awareness and letter naming (Boets et al., 2005). These researchers assert that “to conclude, phonological awareness and letter knowledge turn out to be the best indicators to differentiate between pre-school children with low versus high familial risk of developing dyslexia” (p. 76).

Helland, Asbjornsen, Hushovd, and Hudahl (2007) studied dichotic listening (DL) in relation to school performance in dyslexics. This is referring to auditory perception in persons with dyslexia and not hearing per se. Dichotic listening tasks are usually intended to study selective attentional processes. These researchers state that the nature of the brain is such that stimuli presented in the right ear reach the language centres that are in the left hemisphere of the brain through a direct route, whereas stimuli in the left ear must cross the corpus callosum to reach the area that governs speech processing areas of the left hemisphere. Helland et al hypothesize that: “It has also been suggested that inferences about brain markers of dyslexia can be drawn by relating functional laterality

to poor school performance, and that abnormal cerebral organization underlies dyslexia and learning disability syndromes” (Helland et al., p. 43).

A dichotic listening task is often used to understand the functioning of the left planum temporal area. It provides a behavioural measure that “taps both phonological stimulus processing and would implicate the language areas in the left temporal lobe” (Helland et al., 2007, p. 44). “Typically, an REA (right ear advantage) in the DL task indicates a left hemisphere dominance, involving the left planum temporal area” (Helland et al., p. 44).

There is evidence of reduced right ear advantage on the DL task for people with dyslexia. In addition, “it may be speculated that lack of asymmetry for language representations....could cause perceptual confusion of similarly sounding phonemes” (Helland et al., 2007, p. 49). People with dyslexia tend to switch attention between their ears instead of splitting their attention. One could easily be persuaded that hearing is correlated with diagnoses of dyslexia. It has also been discovered that individuals with dyslexia have different degrees of the disability. Some students with dyslexia still do poorly in school, even when modifications and supports are in place, but others who are given the same modifications and supports when necessary perform well in school. In their study, Helland et al. found that a less severely affected dyslexic group had an REA that was comparable to the control group, whereas a second, more severely affected dyslexic group was lacking REA.

When distinguishing between consonant-vowel combinations, people with dyslexia may confuse similarly sounding phonemes (*t* for *d*) or delete a phoneme (strong-tong). They may also switch phonemes or graphemes (*saw* becomes *was*). It has been

identified that dyslexia is a genetic disorder. Berninger et al. (2008) proffer that although some individuals with dyslexia respond to interventions, others continue to struggle:

Even when these students with persisting difficulties learn to read and spell at age expected levels and are said to be “compensated,” they continue to show behavioral and brain markers of dyslexia. The behavioral markers have been used in studies around the world to identify the heterogeneous genetic basis of dyslexia. These studies have identified the chromosomes linked to specific behavioral measures of dyslexia. (p. 4)

The social issues surrounding dyslexia, such as how the students feel about their disability, deserve the attention of researchers. This is just as important as concern about how students’ brains work and the possible physical reasons they may have difficulty in school. Children are emotional as well as physical beings, so how they feel about what is happening to them profoundly affects their ability to function and develop to their full potential. Once again, students who have dyslexia are sometimes subjected to teasing and bullying by their peers at school. The study of Dutch school children by Singer (2005) attests to this fact. Singer measured the number of children who gave certain responses to her questions regarding the incidence of bullying that the children described: “What happened?” “Who was there?” “What did you do?” “What did you want to achieve by that action?” “Was that important to you?” “What did you feel?” “How did you express that feeling?” and so on. Singer found that 85% of the 51 children who provided a narrative for the study had been teased at school because they had dyslexia. Twenty-five percent were frequently bullied, and 17% did not give a narrative because they had a positive outlook regarding school. The students’ narratives show that children with dyslexia are vulnerable in situations that expose their dyslexia. Some children with dyslexia ignored the bullying and hide their emotions, others defended themselves, and some tried to educate others about dyslexia.

Long, MacBlain, and MacBlain (2007) acknowledge the potential for adolescents with dyslexia to experience emotional difficulties, such as loss of self-esteem, sensitivity to criticism, and alienation from peers. Interventions that go beyond phonemic awareness and include a holistic approach (ie. the student is involved in the direction of his or her own education) that addresses the emotional needs of students have proven more successful. Long et al. describe a phenomenological case study of an adolescent male with dyslexia. Matthew was respectfully included in all of the decision making for his intervention, and he freely shared his feelings of loneliness, failure, and frustration. He was “on the outside looking in” (Long et al., p. 127). Matthew did not feel included in the schooling experience. Once his intervention began, he was able to identify areas in which he excelled in school as well as his weaker subjects. This adolescent male with dyslexia was asked to identify his learning style, and the information was used to fashion a personal intervention. Out of respect for his needs, Matthew’s teachers did not require him to copy notes from the board; instead, they provided him with handouts in advance. He also had a personal dictionary in which he recorded subject specific words. Each teacher would provide these words at the beginning of a topic. He was never required to read aloud in class. Matthew made use of summaries, mind maps, diagrams, and charts to prepare for tests. He also was taught spelling strategies such as simultaneous oral spelling, and his teachers marked his work in his presence whenever possible to facilitate the learning process. He was provided with a mentor who could discuss his feelings with him and advocate for him with his teachers. Matthew was taught study skills and given a visual summary of each syllabus to aid in planning for review. Because he had difficulty keeping up with his work, he used a tape recorder and a word processor. Colour coding

books proved to be helpful. Matthew's parents agreed that he should not be made to do certain household chores if he had an important assignment or test. They also provided an opportunity for him to read aloud daily. This was a very cooperative method involving teachers and parents. (Long et al., 2007).

After six months, "Matthew's reading score and measured cognitive ability was no longer statistically significant, although mild spelling difficulties were still apparent" (Long et al., 2007, p. 128). Matthew's scores on the Wechsler Intelligence Scale for Children III had been lower than expected before the intervention. With the encouragement and support Matthew received after the intervention began he developed a positive view of school and his teachers, and he became motivated to succeed. He felt less lonely and was beginning to fit in. Matthew's attendance improved, and he participated in class more. Overall, he was happier and more relaxed, although homework was still a struggle. This intervention was a success, and this success could possibly be replicated in the lives of other adolescents with dyslexia.

As part of this study by Long et al. (2007), a survey of students with dyslexia was undertaken. They felt that there are advantages and disadvantages to the label "dyslexic," as follows:

Advantages of the label dyslexic appeared to lie primarily in the hope that teachers would extend a more understanding approach to the students if they had a label. Disadvantages of having a label were that others might equate dyslexia with stupidity. (Long et al., p. 130)

Some of the students expressed the concern that they would be belittled by their teachers in class. Many of them also reported that they had been advised how to prepare for and take tests.



McNulty (2003) provides a qualitative look at the experience of persons with dyslexia. However, because his goal was to provide a wide scope of the experience, he did not delve into each of his twelve participants' lives in an in-depth way. His participants were adults looking back on their experiences with dyslexia. McNulty identifies this as the life story method. He asserts that "life story refers to the study of a phenomenon experienced by many individuals through comparing and contrasting the accounts of their lives" (p. 365). In addition, he notes that more investigation needs to be done about the personality traits of dyslexic individuals as well as their emotional experiences.

Fink (1996) describes dyslexic readers who met predetermined criteria that deemed them successful readers. The readers were considered successful if they supported themselves financially, "demonstrated salient characteristics of Chall's Stage 5 reading ability as adults," and showed professional competence in their chosen career (Fink, p. 271). The sample included many different careers such as an attorney, a biochemist, an immunologist, and a theatre set designer. Fink concludes that "IQ did not account for differences in levels of compensation among the adult dyslexics studied" (p. 272), but rather a passion for the material being studied influenced their reading experience. The students exercised extreme effort to learn about their area of interest. Fink also comments, "Presumably, continual frustration with basic skills would lead dyslexics to avoid reading. To my surprise, I found that these dyslexics were avid readers. Although they had persistent troubles with basic, lower level skills....they rarely circumvented reading" (p. 272). The key to understanding for these readers was context and "a burning desire to know more about a discipline that required reading" (Fink, 1996,

p. 274). Because they concentrated on this one discipline, they became experts. With practice, they became better readers. Fink comments, “One overarching implication is clear: Teachers should provide captivating materials based on each student’s strengths, prior knowledge, skills and interests” (p. 277). Parental support is an equally important factor.

Roll-Pettersson and Heimdahl-Mattson (2007) investigated the experiences of Swedish mothers of dyslexic children. These researchers comment on the importance of parental support and advocacy to dyslexic children. The mothers persisted when they were told that “all children are different and develop at their own rate” (Roll-Pettersson & Heimdahl-Mattson, p. 414). If there is no diagnosis, there is often no identification, which often means that the children’s educational needs go unmet. The mothers agreed that structured school environments, whether alternative or mainstream, are the best option for children with dyslexia. The outcome can be different depending upon the students. One mother shared that her daughter felt ostracized in a large class and that this situation negatively influenced her behaviour. A student felt that he missed out on a lot because he was in a special education class. Another mother was relieved when her son found friends after she enrolled him in an independent school with a humanitarian philosophy.

Some of the mothers found that it was necessary to educate the school regarding dyslexia and dyslexic children’s needs. They tended to have to contact with the school if the mothers wanted information regarding their children’s progress. Often, homework was a burden for both mothers and children. As a child gets older, homework can pose a problem if the parents are not current in their own understanding of mathematics or science, for example. Another concern was the balance between being informed of their

children's progress and allowing the children independence as they got older. These mothers found that bolstering their children's self-esteem was a difficult task. Roll-Pettersson and Heimdahl-Mattson (2007) state "Several of the mothers said that their child had expressed not wanting to live any longer" (p. 419). Instead of focusing on the disability, they turned their attention to each child's strengths and talents. In the following chapter about arts-informed research I will explore why this methodology was appropriate to help reveal how Mallory and I each found our self esteem.

### CHAPTER 3: METHODOLOGY

Life is lived and knowledge made through kitchen table conversations and yarnin' at the wharf or transit station or coffee shop or tavern, in the imaginative spaces created between the lines of a good book or an encounter with an evocative photograph, in an embodied response to a musical composition or interpretive dance. These moments of meaning making, however, are not typically thought of as "knowledge." Knowledge, as society has learned to define it, dwells beyond the realm of the everyday. (Cole and Knowles, 2008, p. 59)

The research question guiding this arts-informed case study is, "What is your lived experience as an adolescent female with dyslexia?" This question guided my conversation with Mallory. I also conversed with her parents, asking them, "What is your lived experience as the parents of an adolescent female with dyslexia?" This inquiry is situated in the context of my disability, CP, and the question "What is my lived experience as a woman with a disability, and how does this relate to my participant's lived experience?" Arts-informed research allowed me to explore the truths of my experience as well as those of Mallory and her family. Thomas King says that "The truth about stories is that's all we are, who we have been, and who we will become" (as cited in Cole and Knowles, p. 56).

Arts-informed research came to be as the result of a "dry" period in the research of Cole and Knowles (2008). They found that conventional research was "wrung dry of life-of emotion, of sensuality, of physicality" (p. 58). They found that once they "experimented" with "alternative forms of writing", their research brought forth much fruit; they were invigorated by the "possibilities" of "personal narrative style", the addition of "autobiographical elements" to research as well as "two and three dimensional art, performance, fiction....poetry, literary prose, playwriting, visual arts, dance and music." (p. 58)

The Centre for Arts Informed Research was created in 2000. The work supported there “infuses” the processes and forms of the arts and social science inquiry. Cole and Knowles (2008) posit:

Bringing together the systematic and rigorous qualities of conventional qualitative methodologies with the artistic, disciplined and imaginative qualities of the arts acknowledges the power of art forms to reach diverse audiences and the importance of diverse languages for gaining insights into the complexities of the human condition. (p. 59)

Their objective was not to create art for art’s sake, but to use art as a means to advance knowledge and make it more accessible to a wider audience, beyond the academy.

I concur with Irwin’s (2003) comment:

Everyone can have an aesthetic experience while everyone may not have artistic talent or knowledge of art. Moreover, while aesthetics is derived from knowing through the senses, art is derived from knowing through the transformation of ideas and materials. Finally, emotions are aroused through our sensory experiences. Aesthetic perceptions evoke and provoke emotional responses and, in turn, affect the reception of our aesthetic awareness. (p.72)

Art in its many forms can be used to disseminate knowledge. As with any other methodology, arts-informed research has defining elements and forms. In arts-informed research, the art form or forms frame and define the inquiry process and text. In addition, the form chosen works well to “illuminate and achieve the research purposes.” (Cole and Knowles, p.61). Arts-informed research follows “a natural process of engagement, relying on common sense, decision making, intuition, and a general responsiveness to the natural flow of events and experiences” (Cole and Knowles 2008, p. 61). In addition, the researcher is evident and/or present in the research subjectively and reflexively depending upon the focus and purpose of the inquiry. The researcher’s artistry is predominant, showing conceptual artistry and creative and aesthetic sensibilities but the

research is not exclusively about the researcher. The art “provokes and evokes emotion, thought and action” (p. 62).

Equally important as the defining elements is the form of arts-informed research. The form influences the creative inquiry process. It also “illustrates knowledge production and purposeful communication” (Cole and Knowles, 2008, p. 62). Poetry is a spoken as well as a written artform; different kinds of poetry will influence the communication of knowledge in diverse ways. The researcher must consider the audience and the research itself. One must strive for aesthetic quality. As the research progresses, the form will develop and change. The strength of the research is determined by sound scholarship that is achieved in a way that is congruent with the art form used. Creating good poetry for arts-informed research involves familiarity with different types of poetry as well as using poetic devices. In addition, it was essential to be in touch with the emotion communicated in the data. I found that if I immersed myself in the creative works of other artists with disabilities and the data, I was more inspired. Arts-informed research has a clear intellectual purpose as well as a moral purpose: Ultimately, this research has the potential to transform the opinions of readers.

Between my mind and my pen lies a desert  
 despite lush greenery in my heart  
 An ocean of ink refuses to translate .

I feed my soul the muscle of my imagination  
 Those who have braved the journey before me  
 nourish my mind

Finally able to find fresh dew on the grass  
 I feel a hunger to share

The jet tide washes in many treasures  
 often as the clock strikes twelve  
 My body yearns to find rest but my mind is like the clock...

*Tick tock...* until I sleepily arise  
 and scratch out part of the lyric that is me

I went through a process to create this arts-informed study with a desire to meet the criteria for fruitful arts-informed research. The poem above describes part of that process. I had meaningful conversations with Mallory and her parents. The conversations were co-constructed by the participants and me. They allowed us to explore topics that I may not have anticipated had I only asked questions in an interview format. I then transcribed the tape-recorded conversations. I noted observer comments as well as my reactions to Mallory's journal entries and creative writing. I compared Mallory's experiences to mine as they were written in my journal and my creative writing. Arts-informed educational research is the tool I used to gain a deeper understanding of our disabilities. According to Blaikie (2007):

Arts based educational research draws upon the idea that both image and text (individually and collectively) have inherent meaning. It originates in the practices of studio art and art criticism, that is, in making art, and in writing theoretically, analytically and interpretively about it. (p. 2)

Hence, there is knowledge to be gleaned through informing ourselves of the art that exists now and the art that we create. We cross boundaries and stretch them if we create and write about our art form. Different art forms can inform each other.

McNiff (2008), writing from his own experience with arts-based educational research, communicates ideas about methodology that I also found in the experience of practicing arts-informed research:

My experience consistently reinforced the importance of establishing a relatively simple and consistent methodology for artistic inquiry. The simpler the deeper I say as a guiding principle and this direction is consistent with the way in which science attempts to place controls on variables. Since artistic expression is essentially heuristic, introspective and deeply personal, there needs to be a complementary focus in art-based research on how the work can be of use to others and how it connects to practices in the discipline. (p. 34)

My objective in conducting this study was to explore the topic through meaningful words expressed in conversation, namely, poetry and prose, rather than in interviews. I chose conversation because those involved in the study were on an equal footing. During an interview, the researcher has more control by asking certain questions. In contrast, during a conversation, all parties involved have the opportunity to direct the conversation in unexpected yet fruitful directions. Perhaps this method yields different results because the participants experience a greater degree of comfort. They may also be inspired as the author of a great literary work is when she allows her imagination to roam. Much of this process involves the unfolding of deeper meaning as one examines the data. Gadamer (as cited in Carson, 1986) describes the conversation as follows:

To conduct a conversation means to allow oneself to be conducted by the object to which the partners in conversation are directed... To question means to lay open, to place in the open. As against the solidity of opinions, questioning makes the object and all its possibilities fluid. (p. 76)



Another positive feature of this study is that it allowed me simultaneously to be the researcher and the researched because I sought meaning in my participant's experience and also was able to compare it to my own experience (Drake, Elliot, and Castle, 1993). My goal was for my participant and for me to grow in knowledge and understanding. I concur with Springgay, Irwin, and Kind's (2008) comment that "learning is coming to be understood as a participation in the world, a co-evolution of knower and known, that transforms both" (p. 84). This supports the purpose of arts-informed research because the art created in arts-informed research is not art created for art's sake, there must also be a moral purpose and the creation and dissemination of new knowledge. Finley (2008) asserts:

In looking for higher purpose, such work could offer insight or intentionally exposes audiences to life experiences that they would not encounter except vicariously through their adaptation to an art medium. But to reach an even higher aim of transformative praxis, arts-based researchers need to revisit the importance of the power of form, not only to inform, but also to promote dialogic, performative activist responses among audience participants. (p.79)

My purpose is that this thesis will encourage understanding of persons with disabilities among those who do not have disabilities. The poetry may vicariously bring them to a closer emotional experience of living with a disability. Perhaps they would then be inspired to advocate on behalf of persons with disabilities and they will be more accepting of differences. The current study, informed by phenomenology, may enlighten interested parties because

Researchers in the phenomenological mode attempt to understand the meaning of events and interactions to ordinary people in particular situations.... Phenomenologists do not assume they know what things mean to the people they are studying....Phenomenological inquiry begins with silence.... Phenomenologists believe that multiple ways of interpreting experiences are available to each of us through interacting with others and that it is the meaning of our experiences that constitutes reality. (Bogdan and Biklen, 2007, p. 25)

My participant was encouraged to share her lived experience with dyslexia during conversations which she could steer in whichever direction she wished. I was in a position of being teachable rather than holding to assumptions that I had previously believed. For example, I now understand that Mallory and Leigh do not consider dyslexia a disability. When I read Terzi's (2005) article I tried to keep an open mind about how a disability is no longer a disability when one has the appropriate supports in place.

Drake, Elliot and Castle. (1993) clarify how arts-based educational research reveals valuable insights in their research. They comment, "Behaviour patterns were repeated....often without the conscious awareness of the storyteller. Embedded in these stories were the values and beliefs individuals hold that affect all aspects of life" (p. 293). Because dyslexia is not a disability unique to the young woman whose life I studied, but one that is common to many people, I anticipate that the data I collected would speak to individuals on different levels, informing them about this important topic. Although the interpreted data will be received differently by each person who reads them, the readers will glean knowledge from them. Phenomenology allowed me to understand the lived experience of an adolescent female with dyslexia because it allowed me to explore this phenomenon from the lived experience of each participant. In this method, the informant's experience is distorted the least because she has more control over what is discussed. In addition, multiple data sources can be used (such as Mallory's sketches and poetry) which will reveal more information. Phenomenologists "believe that the qualitative research tradition produces an interpretation of reality that is useful in understanding the human condition" (Bogdan & Biklen, 2007, p. 27). The information, on my participants' lived experience with dyslexia coupled with my reflections on my

experience with CP, may provide new perspectives on disability. For example, my participants saw the phenomenon of disability very differently. Leigh and Mallory see the word “disability” as a negative word and Leigh was concerned that Mallory would be negatively impacted by it if it were used to describe her. Scott, on the other hand, accepts the diagnosis as a disability and saw it only as a limitation that they would have to accept much in the same way everyone must accept his/her limitations.

Saunders (2003) states that in insider research “it is important that I as the researcher acknowledge my preconceptions and theoretical beliefs as much as possible to better understand the participant’s lived experience” (p. 52). She also cites Coughlan and Casey’s (2001) assertion that in insider research, “the researchers are already immersed in the organization and have a pre-understanding from being an actor in the processes being studied” (p. 674). I am an insider in this study because of my history with this family. I have known the participant since her birth, and my connections with her family began years before that. I have been friends with her family since the 1990’s and I have attended the same church as them.

The fact that I also have a disability contributes to my status as an insider (Bowman, 2007). When I undertook this study, I began with the assumption that dyslexia is a disability. However, I had never thought of Mallory as disabled. As previously stated, our diverse views on disability proved to be an interesting theme in the research. My shared belief system with the members of this family also has influenced my creative writing. I assured them that I, as well as the research process itself, would ensure the trustworthiness of the findings. Member checking in particular ensured that all of the

participants were comfortable with the data collection process. In addition, each participant's identity was protected by the use of a pseudonym.

### Data Collection

For this study, I used the following data sources:

1. Tape recorded conversations with Mallory (one lasting 1 hour) and one with each of her parents (two conversations lasting 1 hour each).
2. My journaling and Mallory's journaling (15 minutes per day for 2 weeks).
3. Mallory's creative writing.
4. Mallory's assessment for dyslexia from the Lakehead Regional Family Centre.
5. Mallory also sent me an e-mail in response to a question I posed
6. Field notes which I took right after each conversation

The data sources, especially the journaling, proved to be very informative. Mallory's journal demonstrated to me that her spelling was understandable although it was not perfect. In addition, her changing emotional state was evident. This was not surprising because adolescents often experience a range of emotions along with the changes in their bodies.

I chose Mallory and her family for this study largely because of our closely knit relationship with each other and our long history. I asked Mallory why she wanted to do the study. She replied that she wanted to help me. Leigh also mentioned that they wanted others to be informed about dyslexia. I anticipated that they would be forthcoming about their lived experience with dyslexia and they were.

Mallory wrote journal entries and shared stories and poetry; they shed light on who she is as a young woman, and they highlight the strength that motivates her to do things that are difficult.

Piirto (2002) discusses the issue of the artist's expertise in arts-based educational research. She clearly supports the contention that the artist should have the benefit of knowledge and experience in his or her field, but she also concedes that the work of novices does have value, although experienced artists should be recognized as such. While knowledge of a given art form will enhance a novice's work, I believe that everyone should be given opportunities to celebrate their lives through the arts regardless of their training. Some great works of art have been created by individuals who did not have the benefit of training. Not every work of art is pleasing to everyone, although it seems that some individuals create their art with greater ease. All works of art speak to us in some way; creators of arts informed educational research can teach us about their lived experiences whether or not they have training in a given art form.

I believe that in spite of the fact that Mallory is an adolescent and does not have the benefit of many years of experience, she has the imagination and courage to express herself in creative writing, even though words are at times a source of frustration for her. Her writing demonstrates the strengths within her and her desire to make a difference in this world. It also shows how strong familial relationships can influence an adolescent with dyslexia. Leigh wrote a book about wildlife when she was about 10 years of age and attempted to get it published. She is still an avid reader. This experience gave Mallory the desire to read and write so that she could emulate her mother who represents an example of success for Mallory.

I also have written poetry and other creative works in English and in French. It has been a cathartic experience for me. The experience has allowed me to explore my emotions and look at them in a different way through artful word combinations. Leggo (2008) posits that poetry is “ a way of knowing, being and becoming in the world. Poetry begins with attentiveness, imagination, mystery, enchantment “(p. 168). Leggo also comments, “Poetry is earthy, rooted in everyday experience, connected integrally to the flow of blood in our bodies expressed constantly in the rhythms of our speech and embodied movement” (p. 170). He states that “poetry involves seeking ways to attach ourselves to strong emotion” (p. 168). In this study, I attempt to convey strong emotion via the common experience of disability. I draw on my experiences with attentiveness, imagination, mystery, and enchantment. I concur with Leggo’s statement and argue that that not only poetry but all creative writings are ways of knowing.

Cole and Knowles (2008) state the following about arts-informed research:

Although we operate on the assumption that all research is inherently autobiographical - a reflection of who we are – arts-informed research is not exclusively about the researcher. In other words, although the focus of an arts-informed inquiry may be the researcher herself or himself, it is not necessarily so. (p. 61)

Although only portions of the study are autobiographical, I can still relate to Mallory’s lived experience and comment on it through the poetry I have composed since our experiences are similar in some ways. Reflecting upon Mallory’s and my own written works proved an interesting and informative experience. Perhaps we will have the ability to touch people through our creative writing in a unique way.

## Data Analysis

Saunders (2003) states:

[t]he goal of data analysis in case study research is to create a narrative report which is highly detailed and descriptive. In the process of analyzing case study data, the researcher aims to understand behaviours, issues and contexts of the particular case. (p. 63)

I used the selective or highlighting approach during which one reads, organizes and categorizes data in order to identify themes and explicate the data (Saunders, 2003). In this study, I recorded each conversation and transcribed it, looking for repeated words or synonyms and metaphors that would identify recurring themes. Before the findings were interpreted, I had Mallory's mother verify what was said in each conversation. Because Mallory and her father are dyslexic, it would have been a tremendous amount of work for them to read the transcripts. This process is known as member checking.

The data that my participant deemed the best representation of her lived experience as an adolescent female with dyslexia was expressed in the form of arts-informed educational research. Eisner (1997) states:

When we talk about alternative forms of data representation, assume we mean forms whose limits differ from those imposed by propositional discourse and number. In other words, we are exploring forms of communication that we do not normally use to represent what we have learned about the educational world. (p. 5)

According to Eisner, art forms such as poetry are not conventional ways to express or present research. I have found this to be so in my research. I commonly had the reaction "Why do you have to write poetry for your thesis?" I replied that I enjoy creative writing and that I feel that the presentation of the data has the potential to be richer. Dewey (1958) purports that when one creates, one understands aesthetics in a more profound way. One is "fascinated" by the "colourful drama of change" (Dewey, p. 5) when stoking

a fire. In addition, the reader of poetry is not spurred on “by a restless desire” to arrive at the final solution “but by the pleasurable activity of the journey itself” (Dewey, p. 5).

Looking for the right words to express my thoughts in poetry was an enjoyable but challenging exercise. When I had found meaningful images, I experienced an exciting energy that encouraged me to move forward. The words were like life coursing through my veins.

Arts-informed educational research gave me the opportunity to explore the reality of disability in an alternative fashion. It challenged me as an artist because although I’ve written poetry. I had never explored disability in poetic form before. It challenged me as a researcher because the unique message of our artworks needs to be communicated with care. It challenged me as a teacher because I had to listen to the data, even if they were contrary to what I had previously thought. I hopefully, as a result, will be a better teacher to the exceptional students in my classroom. The findings demand a response from me as artist, researcher, teacher, and human being.

Lymburner (2004) delineates her experience with a visual journal in which she documented her experience visually and in prose. She grew as an artist, researcher, and teacher as a result of reflecting on what she had created. I grew as an artist, researcher, and teacher by composing poetry and prose about myself as well as Mallory and her parents. I grew in understanding the emotions we experienced as persons touched by disability. Before writing a poem, I reflected on the data my participants had shared about their lived experiences with dyslexia, so that I could truly understand the emotions behind their words. I feel that I know each of them better, having conducted this study. Leigh had never before shared with me her heartache when she found out that Mallory had



dyslexia, and how important it had been to her that Mallory succeed academically. Leigh's humility taught me the desirability of this quality. Meditating on this and translating the meditation into poetry was a worthwhile task. The members of this family were very candid in their comments about dyslexia and their reactions to it. As a result, I have deepened my understanding of myself by expressing not only my lived experience as a female with a disability but also my understanding of this family's lived experience with dyslexia. Although this study was not conventional, it may have the potential to reveal useful information to the academic community, teachers, parents, and other interested parties because Mallory's views about being an adolescent female with dyslexia stemmed from her own experience. I anticipate that her views will strike a familiar chord in others. My reactions as a female researcher with a disability also were individual and unique, yet I found aspects of similitude and distinct differences in our experiences. The artistic dimension was as enjoyable for me to experience as it may be for others to witness. Blaikie (2007) comments on the relevance of arts-informed educational research to her research:

I believe the poems speak for themselves, quite independently of me and directly to you. In this sense they are visceral, naked and feral. They speak of survival and pain, of growth and stagnation. They are unlike statistical data which is sanitized and blanketed by notions of objectivity and neutrality. It is very direct communication between me and you that convinces me that visual and poetic research is authentic scholarly work, and a conduit to realize a more expansive tactile visceral and intuited understanding of a particular phenomenon. (p. 24)

My reactions as a female researcher with a disability, also were individual and unique

## CHAPTER 4: FINDINGS

## Family

My life is like a boomerang  
 Bringing back experiences of adolescence through Mallory  
 We spend hours learning from our mothers  
 to be women of strength and compassion  
 Our parents toil to pay the bills  
 then we pump our pedals, burning rubber  
 a favourite activity with our fathers

We are leaders, each the eldest child  
 like debators matching wits or playful boxers, sparring in a ring  
 all the while we hold the flashlight  
 leaving landmarks easy to follow

We experience disability  
 mine visible, her's invisible

She is graceful on stage  
 like a gazelle playing in the grass  
 Flirtatious, her beau leaps like Baryshnikov to catch her eye  
 Their dance confirms the camaraderie of young love  
 They join hands

I hobble on stage and bring to life  
 someone four times my senior  
 The crowd rushes past  
 Some say hello—  
 our eyes don't meet...  
 Through a glass wall, I see the crowd's side  
 smiling, joking, laughing  
 My fingers grope the wall  
 Our hands don't touch...

I read tome after tome with ease  
 Thus begins a love affair with words  
 Ink glides across the page  
 I pour out my life with anticipation!

She bites her lip  
 Words are her friends when they play by the rules  
 They are the enemy when they change the "laws" of orthography

The cause of scarlet cheeks when she's taken by surprise  
But she will accept the challenge!

### Mallory's Family Life

Mallory (a pseudonym) was born in northern Ontario to Leigh and Scott. She is the eldest of three children. In this chapter, her siblings are referred to as Scott Jr., who is 12, and Jean, who is 8. Mallory was a planned pregnancy and was born 1 week over term. The pregnancy and birth were normal. Her motor developmental milestones were reached at an early age, and her speech developed within normal age ranges.

Mallory was born into a middle class family who enjoy a lovely home that reflects Leigh and Scott's artistic inclinations. There is rich colour everywhere in their home. The ambiance is welcoming to friends and acquaintances. Leigh appreciates art, and she also is an accomplished artist in her own right. Leigh and Scott are good communicators and are well educated in their areas of interest, biology and photography, respectively. They are well travelled; some of Leigh's education took place in Great Britain. It is evident that Mallory lives in a privileged, loving, middle class home. Although he has never been formally assessed, Scott believes that he is dyslexic. The fact that Scott is successful in photography in spite of his learning disability has had a positive influence on Mallory.

Spiritual life is very important to them; the family members attend a local church every Sunday. Next to God, Leigh and Scott's children are the most important priority in their lives. They have a strong support system of extended family members and friends. Like other family members, Mallory loves animals. There have been numerous cats, dogs, fish, and sea monkeys in the family home. Although Scott speaks of Mallory with much warmth and care, both he and Mallory admit that she is closer to her mother.

Mallory is not embarrassed to be seen in public with her mother:

I know there's a girl in my class, when her mom comes to pick her up from school or whatever. She's like, "Stay away from me, Mom." She totally has a bad relationship with her mom just because she's embarrassed. She doesn't like to be seen with her mom.... I love it. Like I'll give my mom hugs in public. Like I don't care. I find it really close. We watch movies every Saturday night if we can. We have a bond. I can come to her with anything. It's close. I think it's what a relationship with your parents should be.

Scott commented about his relationship with Mallory:

With me she would go bike riding....bike riding is probably one of the bigger things....You know, I'm hands on but maybe not as heavy hands on as Leigh because she's the first daughter.... I think the second daughter gravitates to the father because it's a different dynamic.

Just the same, Scott did say of Mallory that "she has a caring heart." Whenever Leigh and Mallory picked me up before a conversation for this thesis, Mallory would carry my equipment for me and allow me to take her arm when climbing the stairs. She offered to do this without being prompted by her mother.

Mallory wrote a poem called *If I were in charge of the world*. In this poem she refers indirectly to her experience with dyslexia. The poem is included in Appendix A of this thesis.

Mallory commented that she does not think of her dyslexia unless she has to read a paragraph in class. Still, she offers to read in class. This shows her strength. I have witnessed on many occasions that she has clearly been influenced by her experience with this disability to become a sensitive young woman.

### My Family Life

My disability too has shaped who I am in many ways. I was an unplanned pregnancy, and I was born 2 months premature. My birth weight was approximately 3 pounds. Like Mallory, I am the eldest of three children; I have a younger brother and a

younger sister, both of whom do not have disabilities. It has been suggested that I have CP because the doctor used forceps during my delivery.

My father was a welder, and my mother held clerical positions. We enjoyed a middle-class lifestyle. We did not travel extensively, but we were all encouraged to participate in sports; we also were allowed to become involved other activities that we enjoyed. My preferred activities were Girl Guides, piano lessons, and horseback riding. For most of my life, I felt a nagging loneliness; I constantly yearned for fellowship with my peers. The following poem, which I wrote at 16, demonstrates how I used the piano to escape my loneliness.

#### Poetic Interlude

Approaching the bench I am laden  
With my daily fears and woes.  
Seated now, I shrug my shoulders  
And take refuge in my haven

Fingers dance along the ivory,  
Smoothly, like a waterfall  
Soon I drown in pools of sound  
All else is lost in my reverie

Striking the last chord, I awaken  
Life is bright once again

Playing the piano was especially therapeutic for me in my difficult times of adolescence. While playing, my emotions sorted themselves out. Afterward, I was ready to fight the battles life sent my way. I had strength and hope.

I remember that a young girl who was several years older than I was used to be my constant companion in our neighbourhood as I was growing up. While writing the following poem, I recalled how keenly aware I was of my solitude even at the age of 4 or

Nancy

Rosy light played between the cracks of the back step  
 Vestiges of sunlight bid us say goodnight  
 Until tomorrow...  
 Tears mixed with beads of salt  
 from the heat of the day  
 sting my eyes.  
 All that is left is a board that is broken.  
 Why must she leave?

When my family moved to another part of town, I began my quest for new friends. I was only 6 years of age and naively trusted my new neighbours, the way I had in my former neighbourhood. This was to my detriment. The rules of friendship for one neighbour were different than any I had ever known.

Life was song on a violin.  
 He was a bird of prey seeking a victim  
 I was the dark shadow on barren ground  
 defenseless, frightened, confused  
 a mouse cowering at the prospect of being devoured.  
 Then came the guilt borrowed from that sly fox.  
 Like fruit plucked from its stem before its time  
 I was hard and bitter  
 This “friendship” was far too costly.

Kunkel's (2000) writings gave me the courage to discuss my sexual abuse. She was abused by someone in a position of authority at the missionary school that she attended. This man took advantage of the fact that he was in charge and that the children were taught to be obedient to adults. I was an obedient and trusting child. The perpetrator in my case was an adolescent who also had a disability. He took advantage of me because I was emotionally vulnerable and physically I could not get away from him.

Other disabled females that I know also became victims of sexual abuse. Perhaps the pedophiles saw us as an easy target. Unlike Kunkel's situation, my perpetrator was

not in a position of authority, but I remember feeling that I had to do what he said because he had offered me candy. If Mallory has ever experienced this kind of abuse, she did not disclose it to me. She and her parents commented that she has many friends, so perhaps she is not as emotionally vulnerable as I was. As an adult, I have made many friends, but I also have learned to enjoy my own company.

For most of my education, I attended separate schools; in this way, I was given spiritual nourishment. As a family, our church attendance was sporadic until the birth of my sister. My father attended a Protestant church, which we visited from time to time. At 14, I was more rebellious than Mallory. My rebellion took the form of arguing with my parents. I remember feeling jealous of my brother because he could play hockey with my father. Like Mallory, I spent a lot of time with my mother. I went everywhere with her. I used to go bike riding with my father when I was younger. I yearned to spend more time with him. Later in life, my father made more of an effort to spend time with me. My parents did not get along for most of their marriage; they separated when I was 17 and subsequently divorced. The following poem, which I wrote after reflecting on the contents of my journal, recounts some of my experiences as an individual with a physical disability.

I read the birthday greeting  
 "How glad I am that God made you"  
 A beautiful sentiment  
 Bids me ask myself  
 "How glad am I that God made me?"

Mom's voice in my ears reminds me:  
 "They told us you wouldn't be able  
 to do anything in this life"...  
 But God is the Great Physician,  
 He is the Carpenter, whittling away at my life  
 to finally reveal His masterpiece of enduring quality

I lie between crisp sterile hospital sheets  
 Crying for mother, wishing for the plush comfort  
 of my familial nest like new robins cosseted in spring.  
 "The pain gets worse as you get older", the nurse said  
 Her voice was a jet black ocean of nightmares washing up on my shore.  
 Where is the beacon at the end of this cavern?

But with each operation came a new beginning  
 One foot in front of the other  
 I was stronger  
 Tenacious at the prospect of a challenge.  
 On this birthday I reflect ...  
 Eternally grateful for a sharp mind  
 But my body wilting like flowers in autumn

An unlikely athlete in my own Olympics  
 Arduously trying not to glide on my ankles  
 and to avoid making angels in the snow  
 My parents and doctors told me to exercise.  
 It would be good for me in the long run.

S l o w i n g   d o w n  
 Holes in the sand beside footprints  
 My contemporaries and I in the relay of life  
 with pangs of joy, assisting each other to win in the end

Feeling pain associated with  
 Cerebral palsy in full bloom  
 A flower with curled and brown petals

Am I glad that God made me?"



Family, friends, fortitude  
 And faith.  
 I must say yes!

### Discovering Dyslexia

Leigh and Scott had Mallory assessed for dyslexia by a consulting psychometrist and a registered psychologist when she was 9 years and 4 months old. They used the Wechsler Individual Achievement Test (2<sup>nd</sup> ed.), the Wechsler Intelligence Scale for Children III, and the Children's Memory Scale. They found that Mallory was performing below grade level in reading, mathematics, spelling, and written expression. Her overall intellectual functioning was within the average range when compared to other children her age.

The difference between her verbal IQ and her performance IQ was not significant, suggesting that Mallory "is equally adept at tasks that are highly dependent upon language processing and those that rely on processing visual information and manipulation of concrete materials. However, there is variability among subtests." She "demonstrated high average performance" in the verbal domain and strength in general factual knowledge. At that time, she had a below average understanding of social conventions and mental numerical reasoning skills, as well as below average short-term auditory memory functioning. Within the performance domain, Mallory's demonstrated nonverbal abilities were all within the average range with the exception of the Block Design subtest. Her below average performance on this task suggested weak visual-spatial skills. The findings of the psychologist and the psychometrist indicated that she had a learning disability. Dyslexia was not mentioned in the report, although she and her family were certain that she had dyslexia.

In addition to these professional opinions, her parents had observed some traits in Mallory that were consistent with a diagnosis of dyslexia. Scott shared the following observation based on his personal experience with dyslexia:

I find that she has very similar traits that I do in terms of learning [sic]... She has difficulty with her reading and comprehension because I had difficulty reading and comprehending.... I'd rather look at pictures. I can understand from the pictures what I want to know. She's very much the same. As a child and even now, my mind is very active. It spins all the time. I sleep well, but during my waking time, my mind in school was very active as far as imagining things.... what to do to build things, how to create things, how to view things in a different way.

Mallory wrote in her journal that she was tired and drew a picture of herself yawning. I asked her if one of the results of struggling with dyslexia was being tired. Was she tired because it was the end of the day, or was she tired because she had to read? This was her response:

Just the fact that it was the end of the day. My life's so active because I'm so bouncy and hyper and I get really pooped by the end of the day. Sometimes my mind keeps going, so I have to do something.

Smith et al. (2006) claim that students with learning disabilities may experience difficulties in social interactions, emotional maturity, hyperactivity, and so on. Mallory does not lag behind her peers socially, nor does she lack in emotional maturity; however, her father may have been correct in asserting that their hyperminds have something to do with dyslexia. Perhaps because of her young age, Mallory does not realize the impact of dyslexia.

Leigh shed more light on Mallory's dyslexia:

And then she would come to a point when she would say, "Look, Mommy, I can read the page....I can read the next page for you before I even turn it!" And that was when I began to realize that she wasn't actually reading the words but she had actually memorized the words, which was pretty amazing.... She could look at a page of math....It would be torture for her to do the work but she could look

at a page of math and see patterns in the page....When she would read, she would look at the first letter and the last letter of every word and guess which word fit. So reading for her was like a guessing game. Sometimes she was right, and sometimes, she was wrong.

Further, Leigh noted that although most of us see in our mind's eye how a given word is spelled, Mallory does not know how to visualize the spelling. They had to teach her that skill. Leigh commented, "And so all these things that most people take for granted are learned....they are actually learned responses."

During our conversation, I asked Mallory if her experiences with dyslexia have influenced her so that she has "a caring heart," as both of her parents described her. She answered that she had not read that that particular part of the brain is affected by dyslexia. I asked Leigh about it, thinking that Mallory's answer may have been a reflection of her young age. Leigh expressed that perhaps it had to do with the dyslexia; Scott also is very literal. The intuitive part of their brains may be wired differently. Mallory is very fortunate that her dyslexia does not really impede her socially or emotionally. While she has difficulties with some of her peers, she also has very good friends. Later in this thesis, there are examples of Mallory frustrated with her dyslexia and the next day laughing about it with her family. The change very likely has to do in some part with the fact that she is an adolescent (Ybrandt, 2008) although I do not discount the powerful influence a disability can have on an individual. Adolescents who are able-bodied have many issues to deal with, as do adolescents with disabilities. I believe that having a disability made me stronger in some respects than some of my able-bodied peers. I did not succumb easily to peer pressure and nor did some of my friends with disabilities. I also experienced days in which I was happy being me and other days

when I was depressed. My able bodied friends experienced this as well. For this reason, I do not attribute Mallory's change in mood solely to her dyslexia.

### Dealing with Cerebral Palsy

Like Mallory, I have much to be thankful for. CP may affect gross motor control, fine motor control, and speech, depending upon which parts of the brain are injured. Like Mallory's dyslexia, CP is a complex disability which originates in the brain. Some people use wheelchairs and experience back pain, among other difficulties. At present, my lower extremities are affected more than my upper extremities. I am still able to walk, although I now use canes or a scooter, depending upon the distance I have to travel. When I was 14, I did not use any adaptive aids, and I could climb stairs unassisted. My left hand is weaker than the right, but I was still able to learn to play the piano. My speech has never been affected.

The definition of disability (Smith, Polloway, Patton, Dowdy, Heath et al. 2006) refers to a condition that affects a person's functioning ability, either physical, mental, or both. Leigh and I discussed the topic of recognizing Mallory's strengths. She commented:

And so just beginning to capitalize on the strengths, learning that just because the world would call it a disability, to not look at it as a disability. To look at it as "This is the way I am".... It's not because I'm not normal. I think she's beginning to enjoy the fact that she's "not normal."

Leigh seemed to disapprove of the negative connotations associated with disability. She spoke of a young man whom they know who also has dyslexia: The following poem compares aspects of the young man's experience with Mallory's experience as Leigh describes it. Mallory aspires to be a photographer like Karsh while having skills in the home like Martha Stewart. She may also be a missionary like Mary Slessor.

He dreams of someday getting down on one knee  
 Pride says "You must first show yourself worthy"  
 What will he do?  
 The argument between his head and his heart continues  
 Partner or not, he must provide  
 Unable to solve this conundrum  
 What will he do?  
 Listless, he plays video games into the night...

"She's gorgeous" says her mother; it's likely she'll marry,  
 Lighthearted ribbing encourages humility  
 She dreams of being a good wife and mother  
 Her imagination also sees other possibilities  
 She could be the next Karsh, Stewart or Slessor !

This poem expresses what may seem to some people to be sexist or politically incorrect attitudes. It was expressed to me that even in today's society, this young man would still need to have a job to hold on to a relationship. This young man's pride convinces him that he needs to be the primary "bread winner" in a relationship; he is not, emotionally or academically prepared to do this. I wanted to express these attitudes as closely as I could to the way they were expressed. Leigh describes some of the experiences that cause this young man to be dejected:

I think if you don't understand, you can make it a disability.... [He] has the same thing.... His parents never advocated for him... they pursued all kinds of strange things to help him. They thought maybe a certain kind of pill (we're not talking Ritalin here) could restore equilibrium in the inner ear.... would make him ok all of a sudden.... getting chiropractic treatment on the back of his neck would restore his ability to read.... He's a miserable kid, and he's flunked out of school.... His parents have raised him to be disabled.... They have disabled him. He had IEPs (individualized education plans) all throughout school... special educators all throughout school. A half an hour a day in a different class. So now he's disabled, but it's not from his dyslexia. Dyslexia is a way of looking at the world through a different type of brain. It's not a disability, but you can make it a disability.

.In contrast with this young man, Mallory does not appear to be in despair. She has experienced success in many of her activities. I agree with Leigh that if people treat a person with a disability as though they are incapable, the attitude will render the person helpless; however, the word “disability” does not bother me as much as Leigh because I have always been referred to as disabled and yet I was expected to pull my weight at home and my parents did not allow self pity. This caused me to feel that I was not really profoundly disabled. As my condition changes, I have to accept that I need more help; however, my spirit will never be totally helpless because my family instilled inner strength in me. I have seen similar strength in Mallory. If this young man’s family had pursued an intervention that is similar to that which Mallory’s family did, perhaps he would be better prepared to function in society. I asked Leigh if Mallory has received an official IEP and she indicated that she has not, although they could have her tested orally because she has been diagnosed with dyslexia. Leigh recently told me that if Mallory needs an IEP in high school, she will support it. Mallory also is not seen by the Special Education teacher at her school. Nevertheless, Leigh indicated that Mallory is a high C/low B student. She is not penalized for incorrect spelling unless it is on a spelling test.

### Perceptions of Disability

After having reviewed the transcript of our conversation, I wrote the following poem:

Disability  
Reality and label?  
Go forth with respect

When I wrote this poem, I was thinking that Leigh sees “disability” as a destructive label. I believe that a disability is a condition that affects a person’s functioning ability, either

physically, mentally or both. Some may argue that “dis” automatically makes “disability” a negative term. While this is true, our attitude toward “disability” need not be negative. I do not personally feel that “disability is a destructive label because my parents referred to me as a person with a disability but expected me to be a “normal kid” just the same. I was very capable so I did not feel different from others, yet if someone were to say to me, “You are disabled” it would not seem negative to me. It would be true to my understanding of “disability” I knew that I had to respect Leigh’s point of view as she did mine.

Although Leigh objected to the word disability, she is not in denial that her daughter has dyslexia; as she said, she sees dyslexia as a way of looking at the world with a different kind of brain. She and Scott have gone to great lengths to ensure that Mallory accepts herself and is productive in her life. I feel that if Mallory had been taught that “disability” is not a negative concept it may have worked in her favor. I say this because I was raised to accept the idea that I am disabled, and I am a happy, productive human being. In all fairness, she does not seem to have a negative view of me although she acknowledges that I have a disability. She is not comfortable with the idea of being disabled herself because “disability” is a negative concept to her. The following is my recollection of Mallory enjoying life playing Tiny Tim in *A Christmas Carol* to the delight of a local audience:

That year, Tiny Tim was a girl. She had long, wavy, brunette hair which she hid under a cap to seem more like the little boy born in Dickens’ imagination. She had brown eyes that sparkled with life each time she interpreted the author’s words on stage. Her passion for artistic expression was evident with each word and action. Although her legs were strong and healthy, when she leaned on that crutch, I believed that she knew the struggles that Tiny Tim faced. She too struggles with an impediment, but being a part of the troop made her feel competent. She had a rapport with the others, an easy, comfortable camaraderie with each member of

the cast and crew. I was so proud to know her. For me, the highlight of the performance came when she smiled, "God bless us everyone!"

Experiences such as participating in a play have helped Mallory to discover her voice in this world. She does not feel helpless, nor does she feel self-pity. She has learned that she is acceptable as she is. When I was a child, I was not allowed to say, "I can't." My parents wanted me to have a positive attitude and to not feel helpless. Leigh wanted her daughter to feel empowered, and she feared that the word "disability" would hinder her because Leigh's definition of disability is a negative one.

Scott was somewhat more willing to accept the term:

Disability to me would be that she doesn't have the ability to comprehend the same as a person that has the ability to comprehend. I know how Leigh would say that disability is used in terms of people that have no leg... Disability years ago was a common term that we used for somebody who was not able to do a certain thing.... It's just that in this area of her brain she's not able to decipher codes that other people can.

He believes that even though Mallory is disabled, people do not consider her disabled because her disability is not visual. I told Leigh the fact that if I were to say that I am not disabled, people would not accept it. She thought that the reason may be that CP is visual.

When I was more mobile, I applied to participate in an international choir. All potential members were asked if they had a disability that would impede their performance in the choir. I thought, "I can sing," so I applied. Little did I know that they wanted choir members who could carry luggage, amplifiers, and other pieces of equipment, as well as sing. It was a difficult but valuable lesson for me. I do not see anything negative in using the term disability to describe what I have. Mallory tends to share her mother's opinion of dyslexia:

I don't think I find it as a disability. I just think that it's something that I don't have a strong point in. I'm not good at this or as good as other people. I don't



think of it as a disability. It's just something that I have. I find disability a little negative.

Mallory seems to be in the process of trying to discover how dyslexia fits into her life; she drew a sketch of a girl with tears in her eyes and wrote her name under it with a question mark. I wrote the following cinquain, using words from her journal, as a reaction to this sketch. In a cinquain, the first and last lines are synonyms. At one point in her journal, Mallory says "dyslexia is very much who I am." I added the question mark because at times she does express that she struggles with dyslexia.: At other times, dyslexia does not seem to bother her. She is growing and changing through this experience.

#### Cinquain

Dyslexia  
Frustrating, Troubling  
Laughter, Struggle, Anger  
She doesn't want to feel like that again.  
Mallory?

Is it possible that she is struggling with many issues of identity as adolescents do, and that her feelings about dyslexia are among the things she is trying to figure out As mentioned previously, Leigh shared that Mallory is beginning to enjoy being "not normal". She enjoys being an individual and wants to stand out in the crowd. Dyslexia is another way in which she can be her own person instead of blending into the crowd. She is less likely to succumb to peer pressure, just as I was, because it does not bother her to be different. Still, she does have the desire to read a favourite book and this causes her to struggle. She has come to accept that dyslexia is a part of her life, and tells her friends that "this is her." In her journal, Mallory wrote:

Dyslexia is very much who I am, it is like me, different Not very common [*sic*] I don't know? But I very, well not very often but I get frustrated with it like when there is a book I really want to read but I actually physically can't.... It's emotionally hard. I struggle with it all the time.

Mallory's parents have gone to great lengths to find the appropriate learning situations for Mallory so that she is more comfortable with reading. Because of this, she is able to generally keep up with others in her class.

### My Struggle with Cerebral Palsy

Like Mallory, I struggle with my disability. What I currently struggle with is the reactions of others to my CP. About a year ago, I was substitute teaching, and I thought that things were going reasonably well, considering that I was a substitute. One of the parents approached me the next day and apologized for the class, saying that she had told her daughter that she should listen better and treat me with respect because I was the teacher. Her daughter promptly said, "But she's in a wheelchair." I felt angry and shocked that a child born in today's society would even think such a thing let alone say it. Of course I controlled my anger and her mother and I had a discussion about how important it is for children to learn that these kinds of attitudes are wrong. She told me how she had disciplined her daughter enough to make up for the behaviour of the whole class. She had her write out an apology many times. I was still so shocked that all I could do was listen and basically agree with her. It would be helpful for able-bodied people to understand the lived experiences of persons with disabilities who live with physical and emotional challenges. Persons with disabilities go to school, and when they are finished school, some of them are able to secure interesting and well-paying employment. Everyone should be treated with dignity and respect, regardless of their employment status.

Terzi (2005) offers an alternative view of disability:

A disability is relational both to impairments and to the design of educational arrangements. In particular, impairments become disabilities - that is, functional limitations - in certain educational arrangements, but not in others. Consequently, a disability implies impairment, but the opposite does not hold in all cases. (p. 447)

I can provide a practical example of this view. On my first day working at a large local high school, I took the walker that I had been using for a couple of years. When I arrived there, I could not get to my classes on time; thus, I could not perform my job adequately enough. I was disabled in this situation. Someone suggested that I get a scooter. The next time I taught, I was able to do my job efficiently. I was no longer disabled in this situation. As Terzi purports, I may be impaired, but in my job situation, I am not disabled because I have my scooter. Mallory, too, can use technology such as spell checkers to write correctly. My experiences in school shaped who I am, and they prepared me for the life I lead now. In a few years, Mallory will be able to recollect how her educational experiences shaped her development.

### Education

Mallory's first educational experience was in a public school. Leigh gave me some insight into her thinking at the time:

I was really pro public school because my mom was a teacher. I thought it was the cat's meow and that was the way to go and Mallory's going to get better marks than me. She's going to be A list and all that.

Leigh also revealed the following about Mallory:

She always did really well in JK and SK. She learned her letters really easily. It looked like she was reading books by the end of SK and stuff like that. And then when she was in Grade 1, she began to read to me her books, and she began to tell me.... She would just read them, and I was so impressed. And she was flipping the pages really fast as she was reading them, and I began to get a little concerned.

“Your eyes are not going over the words. You’re just saying what the words are on the page.” So either she was a phenomenal reader or something was weird.

Leigh went on to ask Mallory to tell her what individual words were on the page, but

Mallory could not answer her. The family did not have any effective communication with

Mallory’s teacher:

She was an older teacher, and I’m not going to blame anybody, but she was an older teacher, like 2 years away from retirement, and she was pretty strict. She was pretty...I don’t want to say mean, but she was harsh. She would frequently berate Mallory for “cheating”.... She would frequently call Mallory “lazy.” She would frequently compare Mallory to the boys in the class.... She wasn’t like one of the good six little girls in the class.... She was verbal about how Mallory wasn’t a “normal” girl and she was “lazy.”

de Cosson, Irwin, Grauer, and Wilson (2003) conducted a study in which they placed plaster casts of teachers’ fingers on a coat rack:

I knew I wanted to use the fingers of the cast student teacher hands as they perfectly reflected the anticipated caring with which new teachers embark on their careers. These tangible vestiges of teacher intervention in children’s lives were an inspired vehicle for pointing to our perceived difficulty with whose identity is being taught in schools.... I realized that this translation of meaning from hanging identities to the possibility of manipulation of assigned power differentials of teacher to student was a powerful visual metaphor, one that could be easily “read” from multiple perspectives. (p. 4)

The following poem, by de Cosson, which appeared in de Cosson, Irwin, Grauer and

Wilson (2003) poses a question that all teachers should ask themselves. If Mallory’s

teacher had demonstrated gentleness and kindness instead of being cruel, she may have

been a positive “director” to Mallory’s future rather than a negative one.

Fingers pointing, a directional  
 pattern emerges, multifaceted, non  
 linear, a multilectic opening.  
 Do these fingers engender gentleness,  
 kindness, a pedagogy of openness to  
 their future? Or are they clambering  
 up the ladder of school hierarchies?  
 Teachers as puppeteers with their fingers constantly on the  
 threads of power, controlling movement rather than freeing  
 imagination to wo(a)nder.

I wrote the following poem as a response to Mallory's predicament in grade one, after  
 having read de Cosson's poem:

The teacher looks a lot like Charlotte,  
 tiny, grey and industrious  
 weaving her web to save Wilbur's life

She works hard on her web  
 But it is not symmetrical  
 Because she is blind to some of the needs of the children.

She unwittingly stings with her words  
 Causing wounds which take a long time to heal  
 And impressions which influence who the children will become

Mallory's teacher probably unwittingly caused harm to Mallory, much like a blind  
 spider might. She is trying to create a symmetrical web, or a harmonious classroom but  
 she is unable to because she is unaware of the needs of some of the children. Children in  
 grade one are very trusting of their teachers. They may even think their teachers are  
 perfect. They think that if the teacher scolds them automatically it is their fault.

Mallory began to fall behind in math, reading, and "just about everything." She  
 felt "terrible" at school. It was noted in her assessment that she was experiencing  
 nightmares. Consequently, Leigh took Mallory out of public school and began to home

school her. She was able to explore her own strengths, but she had difficulty with some traditional curriculum. Leigh commented:

So when I began to home school her, I thought it would just be a very simple matter to get her back on track, the reading and....I had all kinds of great texts books and resources, I had phenomenal resources. And it wasn't happening.

Between the ages of 7 and 8, Mallory was tutored by a retired special education teacher, Mrs. Smith. Leigh recalled, "She was amazing! She was crazy!.... Just because she had seen so many wonderful and unusual things in her life, that just made her think that normal was boring! So she was amazing!" With Mrs. Smith, Mallory learned how to hold a pencil correctly, and she began cursive writing and visualizing how words are spelled. One exercise that Mallory recalled involved reading a passage and answering questions about it:

I don't really remember but I remember this one thing I had to do. She gave me an assignment that I had to do, and I detested it. I hated the thing I had to do every week. I had to read. It was a paragraph. Right now, it's like it's so easy like what I did. But it was like a paragraph. I had to read it and answer questions.

Perhaps because she persevered, Mallory now finds the task much easier. Even though she detested this task, she reported that "Mrs. Smith was 'fun.' She was a really cool person....I think she was the one that found out that I was dyslexic and helped me deal with it."

Leigh could no longer home school because trying to teach the school-aged children effectively was a great burden. Of the three children, the two eldest had different styles of learning, and the youngest was still a baby. They decided to enroll them in a small private school. "Good Samaritan" enrolls between 8 and 17 children in any given year. Leigh describes the environment as follows:

Its got a home schooling environment with two profs.... The situation initially was ideal...it really was...the concept is ideal.... It's perfect. It's the one-room classroom kind of thing, where the older kids help the younger kids. You've got two brilliant teachers who know everything. One's a university prof, and the other's a museum curator. It was so creative and so academically incredible.... It was immersion style stuff where you worked on your own. It looked like you worked at your own pace, but it really wasn't because you all had to be at a certain spot when they did the testing.

The premise of the school is that each student will master the tasks given:

The concept of the school is brilliant and she was forced to read.... She was basically immersed in words. Everything she looked at was words. Everything she heard was words. It was just word bombardment, and I think it really did help, too, because she understands words in terms of the flow of words.... Her mind is so amazing; it developed strategies.... She learned how to short form it, how to pick exactly what she needs to pass the test.

Arrowsmith Young (as cited in Miller, 2008) found that affected areas of the brain can be improved "with strenuous mental exercises....written, visual auditory and computer exercises" (p. 35). Her students read multi-syllabic nonsense words aloud, practicing moving the emphasis to each syllable and switching them backwards and forwards. In addition, they read analog clocks among other tasks. She puts a patch over the left eye of a student to strengthen the left side of the brain. While some of her activities differ from Arrowsmith Young's activities, perhaps the stimulation that Mallory was able to get at Good Samaritan allowed her to learn more effectively. At this school, Mallory learned some Latin and Greek; she commented that this helped her to understand words. I noticed when examining her journal that it was relatively easy to read. She spelled words that she did not know by sounding them out. Her extensive work with words taught her to spell most words the way the rules of the English language dictate. She expressed frustration that in English, one does not spell phonetically. When she speaks, she sometimes uses elevated vocabulary. She noted that her mother speaks that

way and her grandmother was a teacher, so she is accustomed to hearing such conversation. In addition, dyslexics often score higher on intelligence tests than is reflected in their school work.

Although this school experience worked well for a time, Leigh and Scott moved their children to another private school that was more like a public school in the way the lessons are taught and the number of students who attend. Mallory stated that even though Good Samaritan was the best school for her academically, Logos meets more of her social needs. Concerning Mallory's academic needs, Leigh asserted:

I've had really good success in the last few years about talking to teachers. The school she's at now is great in that I tell the teachers to forget about spelling. Don't mark it wrong for spelling. If you mark it wrong for spelling, you'll have a problem with me. This is something she'll never be good at, so get used to it.

At the same time, Mallory's English teacher continues to mark the spelling tests. Nonetheless, Mallory does well because of the way in which it is taught. She was proud to share that she had achieved 90% on her last test. She described the process of learning spelling with me:

My teacher was noticing that no one, especially me, was doing well on this curriculum, this way of teaching spelling, so she switched it. I really like the way she does it now. You get your sheets....you get your packet. Whatever you're doing your work on revolves around the words that you're learning. You have to spell it right otherwise you get it wrong....1/2 off or whatever. You have to find out the best answer, and you write that word or write it in a sentence or write it out three times. So whatever you're doing revolves around the word you're learning.

This method of repetition of words sounded very similar to what she had been doing at Good Samaritan with the mastery program. The teachers marked her spelling only in the actual spelling program.



Having discussed Mallory's school experiences with her mother and with Mallory herself, it became clear that she has experienced a wide variety of educational settings, including public school, home schooling, tutoring, and private school. Mallory's education seems to have served her well; she has worked very diligently on her strengths and with even more effort on her weaknesses. I have confidence that she will contribute to society; As her father expressed, "God will have prepared her for the responsibility He has for her." Equally, my school career shaped me in many ways and prepared me for my chosen career.

### My School Career

My first educational experience was at George Jeffrey Children's Centre. Then it was known as the Northwestern Ontario Crippled Children's Centre. In those days, that name was not considered politically incorrect. I enjoyed playing with other children who had disabilities, and I had the benefit of daily physical therapy. There also was a pool where I could swim, an activity that promoted my physical well-being. After Kindergarten, it was decided that because I had average intelligence, I could begin Grade 1 in the separate school system. Mainstreaming was relatively new at the time; I do not remember having any accommodations. I still went to George Jeffrey for physical therapy and to learn how to hold a pencil properly.

In Grade 3, my teacher placed me in the easier reading group. I did not want to be in that group, so I asked for more homework. The teacher promptly placed me in the advanced reading and spelling group. In Grade 4, I went to an open concept school. I think that that school did not have enough structure for me. I began having difficulty in math. I excelled in the subjects I liked (e.g., reading and French) and tried to avoid the

others. I loved books so much that I often would read two or three books per day. I worked in the library at recess, so I knew when all of the good books would come in.

Junior high school brought many challenges; for example, I did not know how to organize my work, and taking notes was difficult. There were no accommodations made for me; letting me photocopy someone's notes would have been a good idea, except that we were given marks for having complete notes. I think that these kinds of accommodations were foreign to the school system at that time, so I struggled along. The following is a creative account of a significant trip I took to Minneapolis with the Grade 10 drama class.

### Field Trip

We chattered away in anticipation of the amusement that awaited us at the end of a long bus ride. Minneapolis promised excitement and learning for budding actors. Among our troupe was a combined drama class of students from Grades 9 and 10 and approximately three teacher chaperones and their spouses.

Our first stop was the Guthrie Theatre, where we participated in an acting workshop that piqued our interest and stretched our young minds. Other theatrical experiences included watching *Pippi Longstocking* at the Children's Theatre. Originally, we thought that we were attending this play to humour the adults who planned the itinerary, but many of us agreed that this performance was the theatrical highlight of the trip.

*My Fair Lady* was being performed at the Chanhassen Dinner Theatre. A friend and I were invited to sit at with our principal and his wife. Our view of the stage was excellent. This also was the first time I had tried a Shirley Temple. In

addition to the drama-related activities, I attended my first baseball game and spent a day at Valley Fair.

On the way home, we went shopping in Duluth. The principal's wife took me to Glass Block to look for a dress because I was graduating from Grade 10 that year. The teachers were always very kind to me. I think that they sensed that I had difficulty fitting in. Their actions took the pressure off the other students, who could just go without being slowed down. What a wonderful trip that was! I wonder how many actors were "born" that year.

In Grade 10, the teachers at that school gave me two honours at graduation: An award for proficiency in French and the Most Outstanding Student Award. When I received these awards, I remember thinking how odd it was that the teacher who presented the awards mentioned how I always had a smile on my face. All I can remember was emotional and spiritual sadness that overshadowed everything that I did. My most vivid emotional memory of that time is pain. I had some friends but I felt that I did not really connect with anyone emotionally. I spent my time dreaming about what life would be like when I had a husband and children. Thinking back, I can say that in a way, I did not make sense because I was far too young to have these things but in another way it made perfect sense because my parents were not happy together. I was determined that my future family would be happy.

Grade 11 brought with it public high school. I took many subjects that I enjoyed: French, English, Spanish, and Italian. I worked very hard and received more honours over the next 3 years. It was an academically challenging school. Unfortunately, I cannot

say that I earned a spot on the honour roll. However, I learned a lot, and some of the teachers allowed me accommodations such as extra time on tests. My English and French teachers definitely prepared me for a career in education.

### Struggling with Dyslexia

I was inspired to write the following poem after completing my study with Mallory about her life experiences with dyslexia. In the process, I rediscovered what a remarkable young woman she is.

ABC's and 1,2,3's  
*I'm the weird one out and I love it*  
 She's not a lost sheep  
 Not a slave to fashion either.  
 She's an individual, the strength of her parents within her.

Upon reading *Dragonsong*, she says:  
*I felt like a failer[sic]*  
 Now *The Tale of Desperaux* now *The Hobbit*...She's hooked!  
 Progressing and evolving to a love of literature...  
 Odd journey for a young woman with dyslexia

Baker Street and The Ballad of Room 403,  
 her chefs d'oeuvres,  
 born of imagination, vigor and promise  
 She writes stories.

*"Friends correct your spelling,...Thanks...*  
*Or your brother or a fifth grader corrects you...hmm!*  
 When teachers correct...ca marche!  
 She plays educator, "correcting" a teacher's foreign accent.

Of math, she says, *I like it, but I suck at it*  
 Her favorite subject  
*I'll figure out what I did wrong. I'll do better.*  
 Drive and determination that give pause  
 to reflect on our own motivation...

She has the last word on her dyslexia:  
*I'm not ashamed of having it. Absolutely not.*

Following is a discussion of Mallory's own reactions to having dyslexia and an explanation of each of her parent's reactions. I then mention the reactions of others, such as her friends, as she perceived them. Mallory seems to feel emotional pain at times because of the challenges her dyslexia presents. She is very close to her mother especially, which is good, but she puts pressure on herself and wishes to please Leigh. A few times during our conversation, her eyes welled up with tears. Perhaps she was touched because I was so interested in her lived experience with dyslexia. She also seems to want to be brave and mature in her situation. This is one of the first entries in Mallory's journal:

The hardest thing for me ever in struggling with my dyslexia was one time my mom said that when she was my age, she read a really amazing book called *Dragonsong*, and my mom bought it for me to read. So I sat down one night before bed and tried to read this book that my mom had loved as a child. And I could not read it. I felt like a failer [*sic*]. I had failed my mom so her [*sic*] and my Dad came in and said/told me that it was ok that I couldn't read it. For me it wasn't. From then on that has been playing in the back of my head, so I try to be careful of what I read because I don't want to feel like that again.

Although Mallory felt devastated at not being able to read her mother's cherished childhood book, her reactions to dyslexia are multifaceted. The very next day, she recounted a humorous situation:

Well, today Jean said something with the dog from Little Racles [*sic*] and his name is Pettey but Jean thought it was P.D. So I said, "No Jean, it's Pettey like, and I spelt it out loud Pettey and Mark says "Petty"? And we all start laughing, it was good any way.

The fact that Mallory is comfortable being the brunt of a joke with people she loves and can trust speaks of her strength of character:

I don't know. It's never really been a big deal.... It's never been like a put down in my family. It's never been "That's just Mallory, she's troubles.... I like the way it's been kind of like a joke....it's funny, and I've just got to live with it....

It's really not that hard to live with.... People find out...they don't really get it. They'd never know if I didn't tell them.

Another emotion that she identified in relation to dyslexia is anger. She commented, "You know, I'm really mad at the writting [*sic*] word making people. I wish they made the words written like they are sounded. It bothers me!"

When asked if she is angry at God for being dyslexic, she replied, "Well, I'm proud of being dyslexic because God made me different from a whole lot of people. I'm the weird one out, and I love it. It's so much fun." Because Mallory and I are both Christians; our faith has helped us to cope with the difficulties of having a disability. We definitely have a different sense of humour though! Personally, I found it difficult as a youth being "the weird one out"; I did not find it fun. Still, I think its important to be able to laugh at yourself. I definitely have learned from her. I do ask myself whether sometimes she still finds it difficult to be "different". It could be that she is finding her place in the world through being dyslexic so she can laugh at herself.

Mallory likes to assert her individuality and her dyslexia is one more way that she is different from others. It seems that being able to explain her difficulties with reading and writing via dyslexia has helped her to cope with these difficulties. "If I didn't have dyslexia, I'd be a weirdo," she admitted. This is one reason why it was important to have the diagnosis. "I'm kind of proud of the way I handle it. I know that I have it but like I don't take advantage or like hate myself for it." Mallory could not recall much about how she felt in Grade 1, but Leigh could. She stated:

At that point, Mallory was pretty self conscious. She was pretty sad and she felt like she was a terrible student and not a nice person, I mean she was only 6, I mean, gee. Imagine that kind of self-esteem starting to go downhill at that point.

The fact that her family is so open and accepting of her dyslexia and supportive of her in general has helped Mallory to deal with her dyslexia. It was not always easy for Leigh to accept that her little girl would be hindered from fulfilling some of the dreams that she had for her. When Leigh had read about dyslexia as well as the origin of schools, she realized that academic success was not the be all and end all of life. Gardner's (2006) multiple intelligences were a key factor for Leigh's discovery of her daughter's unique gifts. After conversing with Leigh to get a sense of her lived experience as the mother of an adolescent female with dyslexia, I wrote the following poem:

### Mother's Cry

*You might consider  
Having her tested for  
Dyslexia...*

The words pounding  
In mother's ears.  
A lifelong sentence of failure.

It's true!  
The lump chokes her...  
Tears obscure her vision;  
dreams are shattered like a crystal castle  
dropped;  
Pharmacy...medicine...  
Stupid dreams.

Pause...breathe... adjust.  
Her expectations were wrong  
Her child teaches her  
Multiple intelligences speak to her  
The world gets bigger  
And bigger.

*Dyslexia..., humbling  
Yet liberating  
One sick little girl-*

But not really...

this is a hurdle she will learn to jump with grace, strength and endurance.

I believe that Mallory will succeed because she has realistic hopes and dreams and plans for her future. She also has her relationship with God to help her with the challenges of being an adolescent and a female with dyslexia. While some individuals with dyslexia choose employment that requires them to read copiously yet they succeed, (Fink, 1996) Mallory's parents have decided to encourage her to use her artistic gifts. She is in agreement and is excited about learning to be responsible for the family business. She also has a great role model in her father who is dyslexic and yet he has his own very successful business.

As previously mentioned, before Leigh discovered that Mallory has dyslexia, she home schooled her:

To my shame, I would get frustrated with her, I really would I would say, "You're not paying attention. You're not trying. These are the rules." I would teach her the rules. "Silent e at the end makes the letter say its name." All these wonderful pithy little sayings. She couldn't remember them, and I would get frustrated, and she felt it.

A friend had her daughter tested for Erlin's syndrome and suggested that Mallory be tested because the two girls had similar characteristics. The woman who did the testing ruled out Erlin's syndrome but suggested that Mallory could have dyslexia. A broken woman filled with motherly love explained to me how she felt at the prospect of her daughter having dyslexia.

I was really sad, You have stupid dreams. She's going to get the marks I did....It was just my stupid expectations....I began to read about dyslexia and school and why do we have school and when did school come about. School came about in the 1700's to keep kids out of the work houses. And multiple intelligences....I began to appreciate different intelligences, different sensibilities and people whose strengths were not just academic....I don't think I really knew how to feel for others. Really, not condescendingly, but really put myself in another's shoes



and go “Wow! Cool, I understand” until Mallory, so it was huge for me. And I love to learn. And you know, so does she. She learns in a different way.

Since her experience with Mallory’s education, Leigh has changed her expectations for all of her children. As long as they are working to their potential, she is content:

I have no false expectations for my children....The whole experience with Mallory has taught me that marks don’t reflect learning. Marks reflect rote memorization or sometimes even conceptual understanding. You can understand a concept and get a good mark....That’s good. If a student doesn’t understand there isn’t learning taking place. There’s not just one way of understanding. When I go to parent/teacher interviews, I always stress I am more concerned about behaviour. I am more concerned about effort. Are they working hard? Are they cooperative? Are they kind?.... Like I said, I measure success in terms of happiness and quality of life and are you good to others. Do people speak well of you....not because you sucked up to them but because you are truly kind and generous and giving and gracious. It’s [dyslexia] really helped me change my focus...

Leigh made these final comments:

God gives you the grace to handle everything. He won’t give you more than you can handle. And the fact that she’s “fearfully and wonderfully made.” She’s made in God’s image. She has God’s gifts in her. I had to recognize that and put aside my expectations, to see God in her. It was amazing. It stretched me, but it helped me to live out what I really believe.

I am in agreement with Leigh that God promises not to give you more than you can manage. From our perspective, we feel that we cannot continue but God created us and knows our limitations and gives us the strength we need. He also uses these trials to cause us to grow, which is what happened in Leigh’s life. I have experienced in my own life that God will even allow a person to experience difficulty in order to bring that person back to Himself. Before I went to France the first time, I was angry with God because my life was not going the way I wanted it to. While I was in France, I experienced culture shock and I did not have contact with my family because they did not have my complete address. Because of these circumstances, I cried out to God and

repented of my anger against Him. My life has been rich in terms of my relationship with God since that difficult time. I grew from my trial just as Leigh had. Although Leigh's initial response to her daughter's diagnosis of dyslexia was to be crushed in a sense, she eventually changed her view and sought out ways to help her daughter. Scott did not have difficulty accepting the diagnosis, probably because he also has dyslexia. Scott was very candid about his lived experience as the father of an adolescent female with dyslexia. He was equally candid about living with the disability himself. This open attitude enabled me to depict his experience somewhat vividly in the following poem. The poem reflects some of the same sentiments that Leigh felt as well:

#### Our Heart's Desire

I've walked the path before you  
 It's a meandering passage with unsure footing,  
 At times you may be assaulted by words such as "Stupid" or "Loser"  
 But don't lose faith...

Your Sentinel is on duty  
 Ready to protect you from cruel onslaughts  
 and to comfort you with His word  
 soothing the affects of pain to your heart, mind and soul.

He labours tirelessly to present you as a refined gem  
 You are His emissary;  
 turn dyslexia from the unassuming sparrow  
 to a bold and beautiful peacock.

We cheer for you from the sidelines  
 And urge you to give praise and thanks,  
 From the palm of His hand.

Scott has a very straightforward approach to accepting Mallory's disability:

So how did I feel when I found out? I'm going "Ok, well she has what I have. What can we do to help her? So I wasn't disappointed she had it. It's just a matter of saying, Ok this is a fact of life. Let's try to help her now because I didn't get any help and I struggled through public school probably more than high school because in public school you're learning a lot of stuff....so I wasn't shocked and going, "Oh, my goodness! She's a dummy kid. She's not going to learn and what kind of job is she going to get!" I just said, "She's probably got similarities in what I had, so what do we do?" What's out there in the government system for teaching and learning?....We said let's get her some help now and that will help fuel her to move on.

Scott's own parents thought that he was merely shirking his responsibilities at school

because they did not have information about such disabilities as dyslexia in the 1960s:

Learning disabilities back then wasn't a key thing that people sort of knew about. I don't think there were any agencies that were there to say "Hey, your kids have learning disabilities". Today there is way more information, education, programs set up....Back when I grew up, it was just a matter of my dad saying "You'd better get good grades on the next report card or else!" So I was kind of threatened into doing good, or doing well in school because there was something coming down at the end that I didn't want to face. So I had to buckle down and do it. I was motivated by fear more than anything else to get good grades to satisfy my parents because they didn't want to have a kid flunking out.

Scott's hope is that Mallory will be able to use her experiences to encourage others. He commented, "Just to be able to take that and say ok, if someone else has that now I'm able to sympathize with them, to come along side them to encourage them that life isn't over because you have this." He concluded with this remark:

I'm glad we were able to catch it early....Get her assessment done....Get her registered as an individual who will need help probably in high school and that it will be available for her because we spent the money to have the assessment made at Family and Children's Services. I think she sees that we were....we went out of our way to do something about helping her....As long as you try hard and do your best that's all that matters. So by encouraging them to try hard and do their best you really, really put their best foot forward. You can't say we want you to have 80's when they're only capable of 60's and making a kid break their brains when they don't have the ability to do it....discouragement, feeling of self worth is down the drain. "I'm no good." You have to get them on the track. "Yes you are good. You just have a little glitch that's not a really big deal.

Reflecting on how her parents helped her, Mallory echoed Scott's feelings about their situation by recalling the plight of a young dyslexic man whom they know:

I'm pretty sure it's dyslexia....The difference is that my parents did something about mine and my writing isn't that bad, like you can understand what I'm saying. His apparently is terrible. He can't read....he actually can't. That's because his parents said, "He has nothing wrong....he has nothing wrong." He'd like give up kind of.

This unfortunate man is 20 years of age, and he has no skills to help him get a job; he has a dejected spirit and little hope for his future. According to Leigh, he is apathetic and does little to contribute to his family. Having seen this happen, Leigh and Scott learned from this family's tragic mistake and took action on Mallory's behalf.

Mallory's family members are not the only people who have reacted to her dyslexia. She wrote in her journal:

I like to be different and the fact that not a lot of people have dyslexia that makes me wierd [*sic*] to some people. I think it's good fun. Because I'll spell something wrong And either 1 or 2 kind [*sic*] of people will be with or around me. #1. The kind of person that would laugh with me or jokingly at me or #2. The kind of person that would make fun of me and because I'm dyslexic I haft [*sic*] to have the right hind of friendship/friend. So in that respect it's hard.

In our conversation, she elaborated:

There are some people who just totally don't care and just accept you because you're you and cool, but it depends on who you're around. If you're around the easy-going, they don't care if you're dyslexic or not, it's really easy to be yourself. Then there are people who....not make fun of you, but try to correct you when you say something wrong, spell something wrong or read something wrong. Then it's a little more harder to be yourself and act the way you are.

Even though Mallory felt that she still cannot reveal her true self with certain people, Scott had assuring words regarding his daughter's social experiences. He stated, "She doesn't have a disability when it comes to getting friends. They think she's cool at

school. She may be different from the other kids at school because she's fairly bubbly and she attracts people."

I asked Mallory if she thought that it has been easier for her because people cannot tell that she has dyslexia or if it has been easier for someone such as me, who has a visible disability. She commented:

Sometimes.... Mostly everyone I know, they know that I have dyslexia. There will be a conversation that pops up, and you've got to tell them. You don't want to keep it away from them, or whatever. But I think it would be easier without it being visual.... My friends, they would have never none [*sic*] if I haven't told them But then if I spel [*sic*] something wrong, they don't really care. Some of my "friends" think their [*sic*] "cool," and they'll spell it the right way. But, whatever.

I think that disabilities that are sometimes less visible depending on the context such as dyslexia or mental illness, are more difficult in some ways because people have automatic expectations of the individual in question. People do not expect me to run a marathon. It is good that Mallory is so frank about her disability because it promotes understanding between the people involved. On the other hand, people can be less willing to reach out to a person with a physical disability because they do not know how to act around someone who appears different. Mallory may have an advantage because she does not appear to be different. People will approach her. Mallory becomes irked when her peers correct her; however, if a teacher does it, she finds the correction easier to accept. Mallory does not like to be put on the spot, that is, having to read paragraphs in class or Bible sward drills (finding a biblical verse quickly and reading it out loud), because she does not want to "mess up." She does volunteer in class because she enjoys literature. Like most people, she is somewhat concerned about what her peers think of her but she will not let this stop her from acting out a play, for example.

### My Supportive Family

My family did everything they could to foster in me the strength I would need to have a productive and fulfilling life. They wanted nothing more for me than contentment and good health. My grandmother and grandfather had a daughter who was developmentally handicapped; when I came along, they had had experience with disability so they welcomed me with open hearts. They did not see me as someone to be pitied, but rather someone to be embraced. The following poem illustrates the special relationship I had with my grandfather.

Tauno

His friends called him "Moose" but I called him Grandpa...  
 I still hear the gentle hum of his voice.  
 His eyes, striking like lapis, watched me with affection.  
 This titan often took me into his lap  
 and embraced me with sturdy arms.  
 I giggled like a gamine when I was with him.

His friends called him "Moose" but I called him Grandpa...  
 He had a farmer's heart although he lived in the city,  
 and often came bearing gifts harvested by his own hands.  
 Our raspberry-filled cheeks appreciated his efforts.

His friends called him "Moose" but I called him Grandpa...  
 He was a grandfather clock at work,  
 following his route even after retirement.  
 He persistently checked each hydrant just like he used to  
 and he stopped for coffee with old friends.

His friends called him "Moose" but I called him Grandpa...  
 A pocketful of shiny quarters quickly found its way  
 into the piggybanks of the neighbourhood children  
 and his own family was not forgotten at birthday or Christmastime.

His friends called him "Moose" but I called him Grandpa...

He took the time each day  
to call me with the latest baseball or hockey scores  
just to get caught up, like two “old souls”

His friends called him “Moose” but I called him Grandpa...

### Ida

My grandmother, Ida, was in many ways my best friend. After school, she was at home with a kind word and a sweet treat that she had made especially for us children. She often told me stories about her side of the family and our Aboriginal heritage. Her sisters would make moccasins and mukluks for us for Christmas. Grandma was a Catholic, and she often encouraged my spiritual growth; I remember going to mass for the Holy Spirit near Mount McKay with her. Grandma liked to pick pine cones and berries, and to go fishing. Even though she was not Finnish, she did not neglect that part of my heritage. Grandma had learned the art of Finnish baking from her mother-in-law, and she passed it on to me.

On one occasion, we started early in the day and made pulla (i.e., Finnish coffee bread) from scratch. She also made wholesome meals like roast beef or chicken and many kinds of vegetables. Once, when I was grown, she packed up a full meal like this and brought it to my apartment on the bus. Sometimes, she would hire a taxi, and we would go shopping or see a movie.

Grandma once told me that she had been praying for me to marry a nice man ever since I was born. From a young age, I was obsessed with getting married. I was far too young to be so serious about such things. One day in late adolescence, I was frustrated about not having a boyfriend. She said, “Maybe you should think about the idea that you might not get married.” I thought, “But Grandma, how could you say that?” I felt hurt

and disappointed that this person who had always been in my corner was giving up. Still, only my grandmother could get away with saying such a thing. Since then, I have dated a few men, but they say that my disability stands in the way. It must be the men that I am dating because I know quite a few women with disabilities who have married. Maybe Grandma was right and I may not marry. My paternal grandparents and I had a special relationship; other extended family members also included me in their lives

### A Home Away From Home

My mother is the second youngest of nine children born to Hortense and Eugene. Many of these children grew up to have families of their own. I was always welcome in each of their homes. As a young child, I remember spending many weekends as a family with Auntie Elaine, Uncle Mike, and my cousins Jennifer and Katherine Anne. The “popcorn song” would come on the stereo, and we children would dance and jump up and down like the fluffy, white snack. Popcorn reminds me of the family film nights we enjoyed at Ogden Community Centre. Wholesome family films were popular.

Auntie Elaine has always been a good influence on me. When I would climb the stairs, she would suggest ways to make it more of a workout for me. She also taught me how to bake and cook, especially butter tarts and cabbage rolls. I got my first chequing account when I was 14 because she suggested it as a way to learn to be responsible with money. I would sit in her kitchen drinking tea and listening to her and my mom talk about the family.



My Uncle Mike loves to make people laugh. Once he made me laugh so hard that I opened my mouth and he stuffed shrimp into it. That was when I discovered that I like the taste of shrimp! That was the first time I had tried it. He is also a great cook. When I returned home from France, I could hardly wait to taste his spaghetti and meatballs. I can taste the sweet, spicy tomato sauce now.

Auntie Elaine and Uncle Mike entrusted me with the care of their children during the day the year I turned 14. They saw that I was responsible and capable. We had a good time that summer.

I often enjoyed myself at the farm of my Auntie Bev and Uncle Art. “Big Donna” (my cousin) taught “Little Donna” (me) how to dye daisies with food colouring. Her sister Sandra loves to laugh. Their brothers Keith and Kenny did not hesitate to perch me on the back of a motorcycle or snowmobile for a tour of the property.

I did not know my maternal grandfather, but I had a special relationship with my grandmother. The day that the Avila Music School opened, my grandmother, Hortense, and I took a special trip to participate in the tour. I was keenly interested in taking piano lessons. There have been many gatherings and enjoyable times with each member of my extended family. To my family, I was just another kid; I could not get away with wallowing in self-pity, although sometimes I was tempted because I did not always understand their expectations of me. As an adult, I understand that they wanted me to grow to be strong and independent.

When I was very young, I had some friends that I spent time with. Whenever I went into the hospital for surgery, my classmates would make gifts for me. They would fight over who could push my wheelchair when I returned to school. The teachers were

always supportive of me emotionally and academically. As I grew older, I ceased to fit in easily, and I had some friends who were not what I had hoped; like Mallory, I had to be careful with these friends because I never knew if I could trust them not to give in to peer pressure. The teachers gave me as many opportunities to shine as they could.

By junior high school, many students would say hello to me, but I felt that there was a wall between us. Oddly enough, the students who had problems with drinking, smoking, drugs, and sex seemed to like me. Perhaps they felt that I would not judge them. I did not really fit in with them because my belief system would not allow me to participate in the activities they chose. I was on a quest to know more about God by the age of 14. Reading the Bible everyday gave me peace of mind. At this tender age, Mallory knows much more about God than I did. She has already participated in believer's baptism. I was still seeking Him. By the end of Grade 13, I had met some friends who shared my interest in spirituality.

Mallory mentioned that she could not read *Dragonsong*, her mother's favourite childhood book which has a lot of figurative language in it. Mallory felt that she was a failure. I could relate to this feeling, although for me, it came much later in life. When I attended the Faculty of Education initially, the building was not accessible. For this and other reasons, I did not obtain my teaching degree on my first attempt. I felt that I had failed, and I had no idea what I was going to do with my life. I tried other options, but I had always wanted to teach. Fortunately, after some renovations had been made to the education building, a good friend suggested I go back. I successfully obtained my bachelor of education degree with a few accommodations such as note takers. I also was allowed to leave certain classes early to get to the next class on time. I was very grateful

for the opportunity to prove to myself that I was capable. Like Mallory, I did not want to feel like a failure again.

### Educating Others about Dyslexia

One activity that empowers Mallory, thus making her less likely to feel like a failure, is that she educates others about dyslexia. Her vehicle this year is her Science Fair project; she chose to do the project on dyslexia. Mallory described some of her research:

We looked up brain images like brain scans of like a dyslexic and a normal person doing the exact same thing and what fires differently in the brain. It was really neat so....It's going to be really cool because I'm writing my Science Fair Project the way I spell things....As long as it's not too far weird. I explain at the beginning, "I'm going to write everything the way I would write it because I'm dyslexic."

Leigh mentioned that Mallory is conducting a survey in the local high schools to compile data. Mallory explained how she was conducting her research:

Right now, I've gone on the Internet and just Googled it. A lot of it will be coming like from my mom. [She] has a whole whack of books on dyslexia because when we were growing up she bought a whole whack of things on dyslexia. She read about it so she knows a whole lot of stuff. So mainly it'll come from books, my mom and the Internet.... The thing about it coming from my mom is that she is going to explain it to me so if I don't understand something, I'll just go to her, and I'll be able to get it, like understand it. I like that my mom knows about it a lot.

Scott supported Mallory's decision to study dyslexia, commenting that

I think it's really good. I think it helps her to see more what it's about. I think that it's going to give her insight as to maybe how it develops or how it starts or how the brain works or why does the brain do that. I think that she's studying and doing a project on something she has. It will no doubt help her to relate to her disability....I think that it will give her some tools to enable her to cope....to help her not feel that she's stupid and incapable of learning....Her doing that project is going to enlighten her as to what it really is about. It will enable her to cope with what she has and to find ways to deal with situations in life.

When I had my conversation with Mallory, she had only just begun her research. At the time of this study, she had placed third in her school competition and was going to the regional competition. Her desire to educate others about dyslexia is being satisfied. I believe that many people will benefit from the fact that she is doing such a personal study.

### Educating Others about Cerebral Palsy

When I was in elementary school, I did a project that educated me about CP. More specifically, it was about the brain. I became aware of the fact that CP is essentially a brain injury before or during birth. This fascinated me, and I enjoyed sharing my findings with my classmates. In addition, I had the honour of being “Tammy,” the female representative of Easter Seals when I was approximately 7. I participated in a fashion show, was presented with a cheque (with an adult) at a hockey game, and attended at least one dinner. I enjoyed bringing attention to a worthy cause, even though I was too young to speak about the disability. Even at this young age, I felt that I was making a contribution. This endeavor had a positive influence on my life; similar to Mallory, I was not ashamed of my disability. Educating oneself and others about a disability certainly has the potential to profoundly impact society.

### Making Life Meaningful

By educating others about dyslexia, Mallory makes her life meaningful. Rather than deny her disability, she is confronting it. Other activities that she engages in also make her life meaningful. Mallory has a love of literature that has not been dampened by her dyslexia. Regarding Tolkien, she commented:

I find when I read out loud, I understand it more....J.R.R. Tolkien, he's very descriptive [*sic*]. I really do like the description. But I have to kind of like

stimulate my imagination. It has to be like good descriptions so that I can like picture it. I do like action too....I love books on tape. The ones I have right now are the Narnia ones. I love those. I love falling to sleep to them and *The Tale of Desperaux*.

Luce-Kappler (2003) asserts:

We need to remember that we are speakers and storytellers, in a community that must hear each other speak, chant and sing as we move our bodies. We listen to and learn from each other engaged in the pleasures of embodied action. (p. 91)

Mallory learns by doing. The kind of learning that Luce-Kappler proposes would be ideal for her. Mallory commented:

I say that I don't like reading but when I get a good book, I love it. I remember when I was little there was this series....It was about this little girl and this bad pixie. I remember I was so pumped whenever my mom bought me a new one. It was like, "Yes, I'd like to read it and finish it." Most of the time, my mom would say, "Instead of watching a movie, why don't you go read." It's like, I don't want to read....I don't like reading. But once I have good book, it's fun, and I have a place to sit down and read it. Then it's good. I like reading.

The evidence of this is apparent on the shelves of her bedroom. Certainly there are movies such as *Titanic*, but there are also many shelves of books.

She also challenges herself by writing:

I really like writing stories. It's good fun because you get to make up the characters. You get to make up everything, like what they look like down to what they act like or what they have as a best friend. Most of my writing has been like stuff that you have to write in school. A lot of it was like Bible work last year. We had to write a story about like you having something and not knowing you had it and it was the best.

Mallory has become more capable of writing good stories because of the advances in computer technology, including spell checkers. She does not find herself in a situation where she is excessively frustrated when doing such an assignment, such as the one she described above. Recently, she wrote the following riddles as a response to reading *The Hobbit* in school:

You need it to live  
 but some don't have it  
 you can find it  
 but it can trick you  
 Who am I?  
 Answer: Love

It's there when you need it,  
 and it's there when you fall,  
 the only way around it  
 is the Lord of all.

Answer: temptation

As previously mentioned, books on tape or CD make reading a more enjoyable experience as well; hence, students with dyslexia no longer have to be excluded from the world of print.

Mallory's favorite activities, as well as her dreams for the future, are realistic in that they keep her talents and skills in mind:

I like to crochet....I like to draw, coordinate colours, help my friends choose paint colours for their rooms....[in the future] I can kind of see myself taking over my dad's business, in a way, just because he's kind of like me. We're kind of like creative.... I can also see myself working in an orphanage.... I've always loved kids, so I could definitely see myself doing that.

When I asked her parents what they see her doing in the future, their answers were consistent with hers. Other options include working in a paint store and interior decorating. The family has not given up hope because of her disability; she is motivated to use her gifts and make the most of the life she has been given.

Many of the activities as well as career aspirations that Mallory enjoys are action oriented Leigh discovered while home schooling her daughter that Mallory does indeed learn best by doing. The home schooling curriculum that Leigh made up reflected that learning style:

She likes to do things. She learns by doing, so we would.... Remember the Japanese thing we did?.... We would read a book like *The Red Clogs*, and we would make a meal, a Japanese meal. We would find Japan on the map, on the globe. We would watch Japanese movies. So totally learn about a culture.... It was brilliant, and she just learned like crazy.... The whole reading thing was always difficult. If you said it to her, she could retain it, remember it, she could say it to you, but if she had to read it, it was really, really difficult.... If we were in a different culture, she would be a dancer.... She bakes, and she sews, and she knits, and she's so good with her hands.... She always had good small motor coordination and gross motor coordination.

Mallory recalled that the years of home schooling were times of rich and rewarding education:

I did like home schooling because we did a lot of other stuff. We didn't really do a lot of spelling and a lot of math and a lot of stuff you're supposed to do. More like artsy stuff....like Egypt....So you'd do what the Egyptians would do and you'd learn it. That's how I learn is by doing it instead of just by listening.

Having knowledge of Gardner's (2006) multiple intelligences has helped Mallory to accept her dyslexia and to maximize the intelligences (ie. bodily kinesthetic) that make her shine. Leigh shared with Mallory the knowledge that she had gained about dyslexia and Gardner's multiple intelligences while she was trying to sort out the issue of Mallory's dyslexia in her own heart. I see this as a sign of the fact that Mallory is supported by her family. Knowledge is powerful and her family wants her to grow to be strong and independent, as mine did. Knowledge will help her to grapple with the issues of dyslexia as they unfold in her life. I think that the more understanding that she has, she will grow in self esteem and self awareness. She is less likely to experience shame over her dyslexia. I think that it is a family responsibility to prepare young people in this way. Mallory's family is not shirking their responsibility.

## Never Give Up

Like Mallory, I have been confronting my disability in a number of ways since childhood. The first of these was a series of surgeries designed to help me walk. After each surgery, I would learn to walk again. In addition to the surgeries, I used canes, “twisters,” and leg braces to help me walk. When I began school, I had therapy to teach me how to hold a pencil and physical therapy to help me walk. I do not remember having any accommodations for or modifications to my work when I was young.

In junior high school, I was expected to participate in physical education. This was very good for me because it made me feel that I was part of the class. I often was asked to be the goalie or the referee. Throughout my childhood, my parents enrolled me in various sports for children with disabilities, including skiing, skating, swimming, and horseback riding. I was in relatively good physical shape because of this. In Grade 12, I lived in France for 3 months, and I became accustomed to walking everywhere. By this time, I had discovered that my intelligence tends to be linguistic. I have studied many different languages over the years. I tend to be able to remember what I hear quite well. This works to my advantage because I write condensed notes in class because penmanship has always been difficult for me.

By Grade 13, some of my teachers allowed me accommodations because I could not write an essay on a test within the allotted time. When they are needed, accommodations and modifications are an excellent way to ensure that students learn. They enable people to confront a disability rather than be overcome by it. When I was in high school, I was encouraged to get as much education as possible. This was good



advice. I have been told that as a female with a disability, I have a better chance of being employed if I am well educated.

Once I started thinking seriously about my career options, teaching became my preferred vocation. I had considered being an interpreter or a translator, but I preferred to get involved with the people I am helping. I thoroughly enjoyed any opportunity I had to teach; of the many jobs that I have tried, teaching is the only one that has totally kept my attention and my passion. These then are some of the challenges that have been present in my life. Confronting them is one way of making life meaningful.

I once had a conversation with a good friend who also has CP. I felt that although I was very mobile at the time and was definitely enjoying my life, the afterlife was going to be that much fuller and richer because my body would be healed. I would then experience things beyond my wildest imagination. She argued that she liked the way she was and did not need to be healed. Now, although I have an abundance of blessings compared to women with disabilities in other countries, I still anticipate the perfection of heaven. Unfortunately, my friend experiences a lot of pain and difficulty with her disability, and she wants to be healed so that she can enjoy the activities that she has dreamed of doing her whole life. She also believes in heaven.

Scott has tried to encourage Mallory with the same hope that my friend and I shared. He stated:

God made you like this. He created you like this; he created me like this. We are living in an imperfect world. Perfection will only be attained when we're in heaven. Don't give up hope. Don't lose heart. Have faith to believe that God has something for you. He will help you because you are in the palm of His hand.... It doesn't matter what you have.... He will enable you to do what He calls you to do, and you will do it well.

Even though Mallory has dyslexia and I have CP we both have supportive family units, which enable us to confront the difficulties presented by these disabilities. Our relationship with God gives us strength.

## CHAPTER 5: CONCLUDING DISCUSSION

As  
     dusk  
         turns  
             night,  
 final  
     rays  
         fall  
             to  
                 reveal

a woman with CP,  
 a student with dyslexia  
 a community convened,  
 a researcher still searching,  
 What does it mean to be  
 a...

I was inspired to write poetry noted in conversations and journaling as well as personal introspection about my own life. The research questions provided a solid foundation for this endeavour. Mallory also wrote some creative works, examples of which are included in this study. Drake, Elliot and Castle (1993) posit that data collection can take an unexpected turn. For me, this occurred during discussions whether dyslexia is a disability, or not. I did not know prior to this study that Leigh and Mallory thought of disability as a negative term. Having reflected on this, I decided that I would rather be able bodied to enjoy all of the opportunities available to me. However, the fact that I am a person with a disability does not cause me to feel badly about myself. In this sense, I do

not consider it a negative term. Scott's response that everyone has weaknesses or disabilities seemed appropriate. Perhaps we can all learn from each other's weaknesses and disabilities.

When I was writing the poetry as a response to the data that I collected from Mallory and her parents, I began to appreciate how strong these individuals were to bare their souls for this study. Their frankness during the conversations and the journal writing enabled me to understand their perspectives on their lived experiences with this disability. As Blaikie (2007) asserts, the poetry that Mallory and I created speaks to each reader independently. My goal is that the reader will become more intimately acquainted with the lived experience of an adolescent female with dyslexia, positioned alongside my experience with disability.

According to Ybrandt (2008), adolescence is a turbulent time in which young people deal with problems or changes in their lives by internalizing them or by acting out. Hair, Moore, Garrett, Ling and Cleveland. (2008) purport that adolescents will flourish if they have the benefit of a positive relationship with their parents. Daddis (2008) finds that peer relationships are especially important to adolescents; parents have control over moral, social, conventional, and prudential matters, whereas peers influence personal and multifaceted issues. I found that my experience was difficult: I much prefer being an adult. Mallory has some difficulties with friends but she seems to cope well.

The study shows that Mallory has an especially close relationship with her mother and that she feels comfortable discussing anything with her. She is generally a contented young woman who likes to laugh and joke with others. The spiritual foundation provided

by Mallory's family has aided her in the struggles with dyslexia, which could have otherwise complicated her adolescent development.

Miles, Haslum and Wheeler. (1998) posit that individuals with dyslexia manifest phonological difficulties, difficulty reading and spelling in relation to general intelligence, confusion over left and right, and difficulty recalling orally presented numerals. Mallory has experienced difficulty with all of these things. Leigh recalled that Mallory had tried Highland dancing, but was unable to do it because she was confused about left and right. In spite of this, finding other pastimes that she could succeed at, such as trampoline, has been very helpful. Cerebral palsy has quite a range of possible manifestations. I am fortunate to be "high functioning". Mallory also seems to be "high functioning" with respect to her dyslexia.

McNulty (2003) declares that persons with dyslexia need an early intervention, encouragement of their talents through hobbies, family support and a search for self worth (ie. spiritual nurturing). All of these elements are present in Mallory's life:

Mallory's family intervened in her situation when she was 9 years and 4 months old. She has been encouraged over the years to participate in various sports and engage in activities that she can do with her hands because she has good fine and gross motor skills. She also is very artistic. Mallory is beginning to explore different employment options, including working in the family's photography studio. The family has taken care of her spiritual needs, which has promoted her self-worth. She does not have an Individual Education Plan (IEP), and she is not penalized for incorrect spelling. Leigh recently told me that if Mallory shows signs of needing an IEP, she will request one.. Presently Mallory is doing well in school and is given the attention she needs in the classroom. At

the time of the data collection, she was achieving low B's and high C's. Now she is earning A's as well. If she needs to be tested orally, she has that option because she was diagnosed with dyslexia. She has supportive family and friends. Scott used the word "encourage" many times during our conversation. My family did many things such as taking me to doctors and encouraging me to do sports in order to improve my physical well being

Mallory and her family have acknowledged that she has dyslexia. However, not everyone in the family considers dyslexia a disability. As Mallory stated, "It's just something I don't have a strong point in. I'm not good at this or as good as other people." If Terzi (2005) is correct in her definition of impairments versus disabilities, perhaps Mallory does not need to think of herself as disabled. In McNulty's (2003) study, the participants reported feeling that "something's wrong with me." Mallory did not verbalize this sentiment, but she did express feeling like a failure when she tried to read *Dragonsong*. Even though the word was on her mind from then on, she was not ashamed of having dyslexia. My family always considered me disabled but I was expected to pull my weight as a member of the family

Leigh acknowledged that she helped Mallory with her Science Fair project. According to Singer (2005), "On average, the parents provided more help each week than the professionals did" (p. 415). This is in regard to hours spent with the student working on homework.

Some possible childhood emotional problems include anxiety and depression, reluctance to go to school, physical complaints leading to avoidance of school, and fear of failure in school (McNulty, 2003). Mallory does not remember Grade 1 and says that it

was more difficult for Leigh than for her. The assessment for dyslexia mentioned that she was having nightmares. When I asked her if she felt anxiety or physical pain, she replied that she did not. Mallory may have avoided missing school and bullying because she was home schooled for a time and went to private schools that had few students. She also has a bubbly personality which attracts people to her.

Mallory did not report having experienced any bullying to date in her school career. Just the same, Singer's (2005) findings about bullied dyslexic children revealed profiles of children that are in some ways similar to Mallory such as the need to educate others about dyslexia. I often felt that I did not fit in with my peers; however, I was never bullied. I also had a keen interest in being educated and educating others about my disability.

Although Mallory did not disclose any experiences of being teased or bullied, she did say that she had to be careful about choosing her friends and that she could not be herself around certain people. She has a strong desire to educate others about dyslexia. Mallory does not hide her dyslexia from anyone because she seems to feel that this would be dishonest. Leigh commented that Mallory has begun to enjoy "not being normal". She does not seem to worry about stigma. This could be because of her spiritual strength. Our spiritual strength has helped both of us not to give in to peer pressure.

Another aspect of Mallory's personality that helps her to cope with her dyslexia is her humour. Mallory does not mind being the brunt of a joke, and she laughs with people. When I asked her what she is proud of, she did not hesitate to mention other people's accomplishments, but was very modest about her own achievements. She said, "It's fun" rather than "I do this because I'm good at it or because it's one of my strengths." I also

have learned not to take myself so seriously. I do things because they are fun and good for me (e.g., sports).

Mallory is very self-motivated to complete her homework. Dyslexia certainly has impacted the amount of time Mallory that spends on her homework as well as many other aspects of her life. Mallory does many things that are difficult for her because she has been encouraged by Leigh, who enjoys learning and all of the activities that it entails. Fink (1996) declares that reading material that the student with dyslexia finds interesting can spark a passion in that student. It is then more likely that a student with dyslexia will pursue reading on their own. Mallory keenly wanted to read a series about a pixie when she was younger, and she now reads books such as *The Hobbit* with relish. Her interest in the fantasy of these novels, coupled with a desire to be like her mother, has contributed to the success she has had in reading.

Dyslexia also has affected the lives of Mallory's parents. Bull (2003) states that some parents of children with dyslexia inform themselves about dyslexia through support groups and other means in order to help them cope with the disability. Although Leigh did not seek out a support group to help her deal with Mallory's dyslexia, she had the same motivation to educate herself about dyslexia. She availed herself of books and other media to become educated about dyslexia, which has helped Mallory to understand and accept dyslexia as a part of her life. Bull also described some of the parents in her study as seeking out the comfort and empathy of others. Leigh received support from family and friends, especially one friend whose daughter has Erlin's syndrome. The two girls were very similar in age, symptoms, and home schooling experience, so the mothers supported each other.



As a child, neither I nor my parents were involved in support groups designed to help me cope with my disability. However, we did get involved in recreational activities for persons with disabilities. This helped me to deal with my disability and allowed me to meet others with physical disabilities. During my early years in school, I was the only student who had a physical disability. I had no close friends with disabilities until high school. Several organizations for persons with disabilities have become part of my adult life. They have informed me about my disability and other disabilities. My involvement in the organizations also has given me the opportunity to educate interested parties about disability-related issues.

Completing this study was an attempt to let the voices of females with disabilities be heard. There will be more understanding if there is more dialogue. Perhaps the Mallorys of this world will then feel that they can be comfortable and accepted being themselves with more people. Perhaps fewer young females with physical disabilities will experience a wall between themselves and their peers the way I did as a youth. The answer to these issues is not to segregate persons with disabilities into special schools. Both Mallory and I can attest to the benefits of integration into the regular classroom setting. This arts-informed educational research study allowed us to come to know ourselves and each other better.

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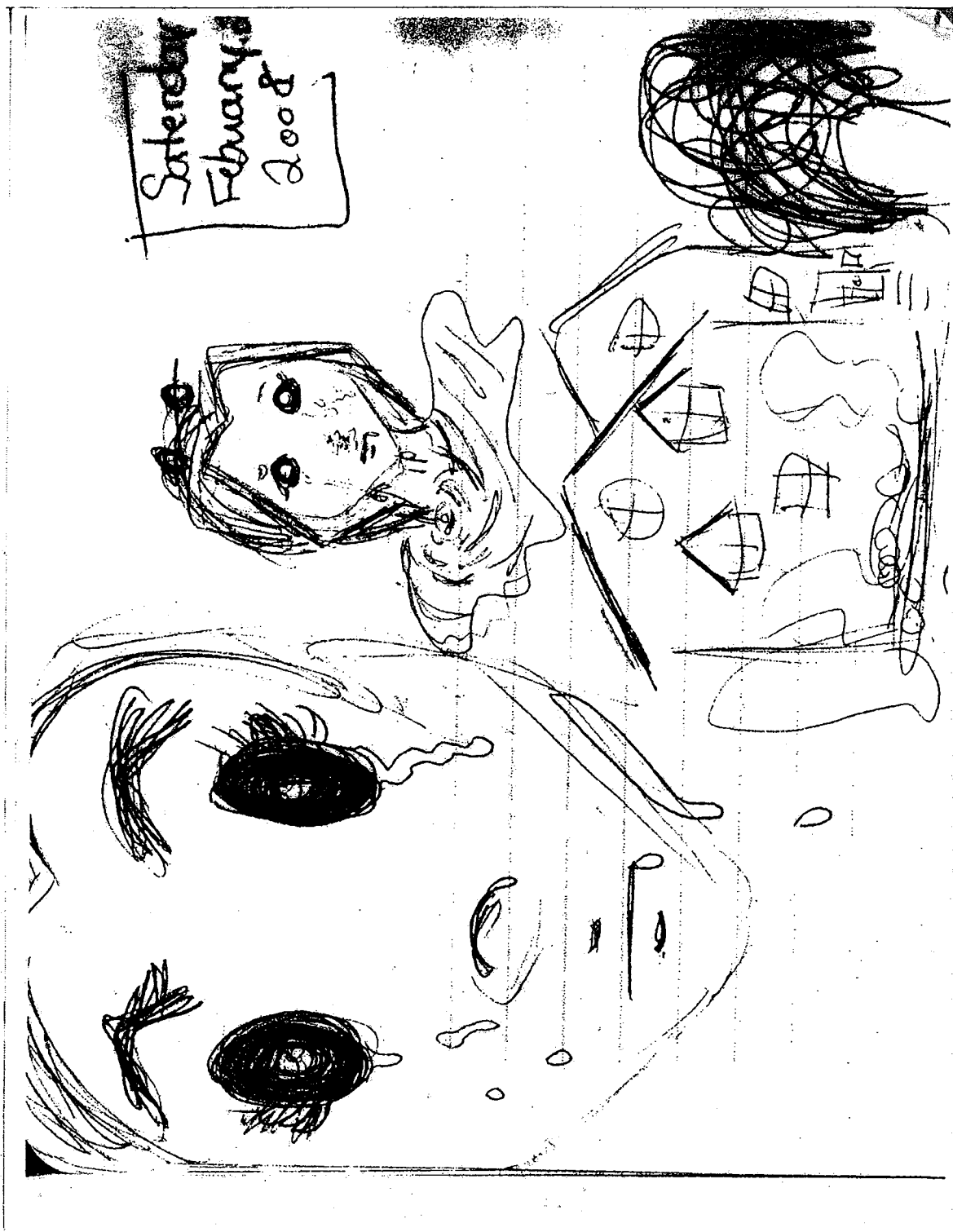
## Appendix A

If I were in charge of the World

If I were in charge of the World  
my sister would have her own room  
my brother wouldn't be smart  
only moms would eat raisins and dads would play with their kids twenty-four  
seven  
there would be no school!

If I were in charge of the world  
there would be no depression  
there would be huge food stores all over the world and the food would be free  
there would be no such thing as money  
everything is free  
there would be no wars  
and no negative comments  
and no bullying in schools  
and someone who couldn't spell cereal could  
be in charge of the world

## Appendix B



## Appendix C

## Conversation with "Mallory"

**Donna:** "Mallory" can you tell me what your life experience has been as a teenaged girl with dyslexia?

**Mallory:** It's been interesting because I've had totally different responses to me being dyslexic. There have been a few people who don't really like it, who think you're weird because you have it. There are some people who just totally don't care and just accept you because you're you and cool but it depends who you're around. If you're around the easy-going they don't care if you're dyslexic or not, it's really easy to be yourself. Then there are people who... not make fun of you but try to correct you when you say something wrong, spell something wrong or read something wrong. Then it's a little more harder to be yourself and act the way you are.

**D:** In your journal, you wrote that there are some friends, just like you were saying today, that accept you and some friends, they correct you. How do you feel when they correct you?

**M:** Not really put down but disappointed in myself. "Oh, I spelled that wrong, darn it." That I should have done it right the first time. It depends on what mood I'm in. Either that way or "I don't care, I'm going to be like this for the rest of my life. Then I just get on with it. But it depends who it is and what mood I'm in."



## Appendix D

# Lakehead

UNIVERSITY

Faculty of Education

Dear Potential Participant:

I would like to invite you to participate in an arts informed educational research case study focusing on the lived experience of an adolescent female with dyslexia. Much of the current research finds that there are more males who have dyslexia than females. The experiences of females with dyslexia have not been as widely studied.

As a Master of Education student at Lakehead University, I am pleased to be conducting this research. My study is entitled "An arts informed educational research case study on an adolescent female with dyslexia." The purpose of this study is to provide information about the experiences, struggles and triumphs of an adolescent female with dyslexia. My main research question is "What is the lived experience of an adolescent female with dyslexia?"

Involvement in the study will take a maximum of 7 hours of your time. The following are the activities in which you will be involved:

- We will have approximately two videotaped conversations lasting one hour to an hour and a half each. (3 hours)
- You will journal for fifteen minutes a day for two weeks. (3 ½ hours)
- You may wish to write poetry in order to express your thoughts and reflections (this will involve an additional period of time, as yet undetermined; it is up to you to decide).
- You may wish to create artwork which reflects your experiences with dyslexia (this will involve an additional period of time, as yet undetermined; it is up to you to decide).

Your participation is completely voluntary; you may withdraw from the study at any time. You may choose not to answer any of the questions asked of you. The conversations that we have will be tape recorded.

There are no foreseeable risks harms or inconveniences involved in your participation in this study. One benefit of your participation in the study is the possibility that you may help others to understand your disability. You will also have the opportunity to reflect on your own disability. A pseudonym will be used in order to protect your identity; however, because of our close association with each other, there is the possibility that people may be able to deduce that you are a participant in this study. The results of this research will contribute toward a thesis which will be available in the Lakehead University Library

My supervisor and my committee member will have access to the data as well as me. The data will be stored at my residence during the research period and at Lakehead University for seven years after the study is completed. You will be invited to verify all of your contributions to the research; you may contact me at any time in order to access the results of the study. My telephone number is 345-7541. My supervisor is Dr. Fiona Blaikie ([fiona.blaikie@lakeheadu.ca](mailto:fiona.blaikie@lakeheadu.ca), phone-343-8222). You may also contact the research ethics board, (Lisa Norton, Research Office, [lnorton@lakeheadu.ca](mailto:lnorton@lakeheadu.ca), phone- 343-8283). If you wish to participate, please sign and return the attached consent form.

Sincerely,

Donna-Lynn Wiitala

## Appendix E

# Lakehead

UNIVERSITY

Office of Research

January 18, 2008

Tel (807) 343-8283

Fax (807) 346-7749

Ms. Donna-Lynn Wiitala  
Faculty of Education  
Lakehead University  
955 Oliver Road  
Thunder Bay, Ontario P7B 5E1

Dear Ms. Wiitala:

Re: REB Project #: 050 07-08  
Granting Agency name: N/A  
Granting Agency Project #: N/A

On the recommendation of the Research Ethics Board, I am pleased to grant ethical approval to your research project entitled, "An arts informed educational research case study".

Ethics approval is valid until **January 18, 2009**. Please submit a Request for Renewal form to the Office of Research by December 18, 2008 if your research involving human subjects will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Research Ethics Board forms are available at:

<http://bolt.lakeheadu.ca/~researchwww/internalforms.html>

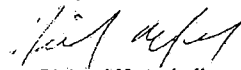
During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Completed reports and correspondence may be directed to:

Research Ethics Board  
c/o Office of Research  
Lakehead University  
955 Oliver Road  
Thunder Bay, ON P7B 5E1  
Fax: (807) 346-7749

Best wishes for a successful research project.

Sincerely,



**Dr. Richard Maundrell**  
Chair, Research Ethics Board

/len

cc: Dr. Fiona Blaikie, Supervisor, Education  
Faculty of Graduate Studies  
Office of Research



955 Oliver Road Thunder Bay Ontario Canada P7B 5E1 [www.lakeheadu.ca](http://www.lakeheadu.ca)